



## State Summaries of Lifespan Respite Grant Activities





## Contents

**1** Introduction and Acknowledgements

### 2013 Grantees

First Time State Grantee

**3** Idaho

Integration and Sustainability Grantee

**5** Oklahoma

### 2014 Grantees

First Time State Grantee

**9** Arkansas

Integration and Sustainability Grantees

**11** Alabama

**13** Colorado

**15** Iowa

**17** Massachusetts

**19** Montana

**21** Nebraska

**25** Nevada

**27** New York

**29** North Carolina

**31** Rhode Island

**33** South Carolina

**37** Tennessee

**39** Texas

**41** Virginia

**43** Washington

### 2016 Grantee

First Time State Grantee

**45** Maryland

### 2017 Grantees

First Time State Grantees

**47** North Dakota

**49** South Dakota

Advancing State Lifespan Respite Systems Grantees

**51** Alabama

**53** Arizona

**55** Colorado

**57** Idaho

**61** Nevada

**63** New York

**65** North Carolina

**67** Oklahoma

**69** Rhode Island

**71** South Carolina

**73** Tennessee

**75** Washington

### 2018 Grantees

Advancing State Lifespan Respite Systems Grantees

**77** Arkansas

**79** Massachusetts

**81** Montana

**83** Virginia

Summaries from some state grantees were not included in this report for certain years because the state does not have a current Lifespan Respite grant; the grantee did not provide sufficient information; or more recent grant information was available for that particular state and included elsewhere.

## Introduction and Acknowledgements

The Administration for Community Living has administered the federal Lifespan Respite Care Program since 2009. When they announce a funding opportunity for states, leaders in the field of lifespan respite across the nation put pen to paper to apply for funding to support their state's lifespan respite system. In writing, they record the collective aspirations for caregivers and care recipients in their state, consistent with their state's particular resources, needs, values and beliefs.

The Federal Lifespan Respite Care Program outlines five objectives that state lead agencies must honor should they receive a grant award.

- 1 Expand and enhance respite services in their state.
- 2 Improve coordination and dissemination of respite services.
- 3 Streamline access to programs
- 4 Fill gaps in services where necessary.
- 5 Improve the overall quality of the respite services currently available.

These objectives are important in fulfilling the purpose of the Lifespan Respite Care Program – to create **coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs.**

Approaches to meeting these objectives are by necessity flexible rather than prescribed, allowing individual states to create, shape and refine lifespan respite systems according to their state's unique circumstances. Across the nation, certain approaches emerge as popular and useful – collaborative partnerships with agencies, programs, and caregivers; no wrong door ports of entry for caregivers to receive services; statewide websites and data bases providing information and access to services; and recruitment and training of respite providers and volunteers to address the workforce shortage. Many grantees may also offer discretionary mini-grants to community and faith-based agencies to expand respite services; volunteer respite options; emergency respite services; and self-directed respite vouchers to help families pay for respite – for example. But each state will have a unique way of designing and carrying out goals and activities related to these.

In the following summaries of state Lifespan Respite grant objectives, outcomes and activities since 2013, you have an opportunity to discover these unique approaches, to learn from them, and – we hope – to begin or continue a dialogue around topics important to you with other leaders across the nation, and with key partners in your own state. The information is also intended to inform policymakers and funders about innovative solutions that are being developed at state and local levels to advance access to respite and caregiver supports at a time when the need is escalating rapidly. From these vital and timely summaries, ARCH hopes to capture best practices in the design and implementation of Lifespan Respite systems and services to guide continued policy and program improvements.

### Acknowledgements

ARCH wishes to thank the Lifespan Respite grantees who graciously shared with us their grant proposals, semiannual and final reports that were previously submitted to ACL to meet federal grant requirements. We also want to thank them for taking the time to review the content of their prepared state summaries.

This product could not have been completed without the tireless work of Susan Janko Summers, PhD, ARCH Consultant, who was the principle author of this document. She spent countless hours reviewing the many proposals and reports submitted by the grantees and drafting the summaries of each state's Lifespan Respite grant objectives, outcomes and activities. ARCH is also grateful to Vivian Gabor of Gabor & Associates Consulting who assisted in preparing a number of the summaries, and to Norma McReynolds for her graphic design and layout.



For more information, visit [www.archrespite.org](http://www.archrespite.org)  
or contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Respite Network and Resource Center.

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Idaho Commission on Aging (ICA)**

Funding Period: **2013-2016**

Primary Goal: **To establish a Lifespan Respite Program that expands and enhances respite services and improves access to respite throughout the state for family caregivers of people of all ages.**

Key Performance Measures	Notable Achievements
<p>The Idaho Commission on Aging, working with the Boise State University Center for the Study of Aging and the Idaho Lifespan Respite Coalition, now called the Idaho Caregiver Alliance, conducted needs and assets assessments, gathered formative data on activities, and reported data on outcomes linked to each of their five objectives. These data were presented to stakeholders during formal presentations and in written documents available through Idaho Caregiver Alliance and Idaho Commission on Aging.</p>	<p>During the funding period, membership in the Idaho Lifespan Caregiver Alliance increased from 47 to more than 300 persons and organizations. The Idaho Caregiver Alliance (ICA), supported by the Idaho Commission on Aging (ICOA), created a Concurrent Resolution for passage during the 2017 Idaho Legislature. The purpose of the Concurrent Resolution is to raise awareness about the value of caregivers, their challenges, and the importance of implementing the Action Plan.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Enhance the Idaho Caregiver Alliance (ICA).</b></p> <ul style="list-style-type: none"> <li>• In order to harness the expertise of the ICA and maintain each organization’s commitment to the project, quarterly meetings were held to discuss activities, decide next steps, and learn about programs.</li> <li>• At the onset of funding, Boise State University–Center for the Study of Aging (BSU–CSA), the lead agency for the ICA, conducted a statewide caregiver survey to inform planning and guide subsequent work, and created content for an online respite and caregiver support resource database and web-based access.</li> <li>• Based upon a list of issues, priorities were identified and three workgroups formed in order to identify activities and products: Supports for Family Caregivers; Information, Education, and Public Awareness; and Health Professionals Practices.</li> <li>• The ICOA and BSU-CSA created the Idaho Lifespan Family Caregiver Action Plan, a roadmap for how Idaho can support family caregivers of people of all ages. The Plan, the result of more than two years of discussion, research, outreach, deliberation, and dedicated effort by diverse stakeholders, which carefully considers how to build upon existing partnerships and resources, will be used to increase awareness among policy and decision-makers, stimulate dialogue and planning, and catalyze interest and resources to improve the family caregiver environment.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• The first stated objective of the grantee is: “Enhance the Idaho Caregiver Alliance.” The ICA was tasked with building a sustainable, functional statewide advocacy network that would continue to improve lifespan respite support.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>• The ADRCs, comprised of the six Area Agencies on Aging, and the three Centers for Independent living, are key partners working collaboratively with the ICA to achieve Objective 2 proposed by the grantee: “enhance information about, and access to, respite care through established information and access points.”</li> </ul>

**Objective 2: Enhance information about, and access to, respite care through established information access points including the Aging and Disability Resource Centers (ADRCs).**

- At the onset of funding, the ICA Marketing and Sustainability Workgroup met and developed a “Dream List” of elements to include within a statewide online services and information website and assistance organization. Their initial work guided subsequent activities to make the website a reality.
- ICOA (Idaho’s ADRC), ICA, and 211 Careline collaborated to create a caregiver respite landing page on the 211 Careline website. ICA developed content for the 211 Careline landing page.
- AARP Idaho collaborated with the ICA to create the *Resource Guide for Idaho Family Caregivers*, which includes resources throughout the state for caregivers across the lifespan. AARP Idaho printed and distributed 2,000 copies of the guide statewide and provided access to the guide.

**Objective 3: Conduct regional meetings to identify and address strengths and challenges of current respite services.**

- At the onset of funding, the Regional Connections Workgroup interviewed other states to learn how they engaged regional groups in statewide planning for Lifespan Respite.
- In 2016, a regional summit was held with multiple stakeholders participating. The ICA obtained funding to support another Lifespan Respite Summit, held in July 2017.

**Objective 4: Identify current training opportunities, identify gaps in training, and develop and provide training to respite providers and volunteers.**

- A caregiver needs assessment, and a respite resources assessment, were conducted, and data were used to inform this objective. Using Powerful Tools for Caregivers (PTC) as one strategy to realize this objective, nine PTC trainings were held across the state during 2016 in partnership with Jannus Corporation’s *Friends in Action*.
- Based upon a recommendation in the *Caregivers in Idaho* report, a state registry of respite providers was established.

**Objective 5: Provide emergency respite services.**

- At the outset of funding, a Statewide Needs and Asset Assessment Workgroup formed in order to gather information for planning, and the Workgroup prioritized emergency respite activities in subsequent years.
- An emergency respite care pilot program was launched during 2015 through a contract with the Federation of Families for Children’s Mental Health.
- After completion of an Action Plan addressing emergency respite needs and other priorities identified by the Workgroup, the ICA planned one-to-one meetings to educate key stakeholders about the value of caregivers, their need for both occasional, emergency and ongoing supports, and the importance of creating a funding mechanism for implementation of the Plan. The ICA anticipates a funding request during the 2018 legislative session.

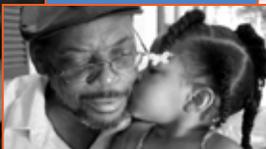
**State and Community Partners**

- Six Area Agencies on Aging (AAAs) serving as local ADRC sites
- Idaho Caregiver Alliance (ICA)
- Boise State University Center for the Study of Aging (BSU-CSA)
- Idaho Assistive Technology Project at the University of Idaho’s Center on Developmental Disabilities
- Idaho Department of Health and Welfare, Divisions of Medicaid, Public Health and Behavioral Health
- More than 20 public and private agencies and programs representing persons likely to need and use respite throughout the lifespan.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Oklahoma Department of Human Services Aging Services Division (OKDHS AS)**

Funding Period: **2013-2017**

Primary Goal: **To integrate, expand, enhance and ensure the sustainability of lifespan respite services in Oklahoma.**

Key Performance Measures	Notable Achievements
<p>To document their work, Oklahoma measures: expanded respite services and choices; reduced out-of-pocket expenses for respite services; improved independence for caregivers and care receivers; improved physical and mental well-being of caregivers; sustainability of at-home care for care receivers; reduced negative impact on caregivers' out-of-home work; caregiver satisfaction with respite services received; use of the ADRC as caregivers' source of information and referrals on respite services; training provided for caregivers, long-term care professionals and care recipients; and enhanced public knowledge of lifespan respite.</p>	<p>The lead grant agency provided seed grants to four community organizations who established grassroots partnerships within their communities allowing grantees – through outreach for the respite voucher program and development of new locally tailored respite services – to reach areas of the state and caregivers previously not served.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Provide seed grants to bring to scale, and enhance respite care services.</b></p> <ul style="list-style-type: none"> <li>Seed grants were awarded to four community-based organizations who used innovative respite service delivery models: <ul style="list-style-type: none"> <li><b>Single Parent Support Network</b> provided services to support grandparents raising grandchildren. Direct respite was provided to single grandmothers caring for grandchildren at a notable event, Queen for a Day.</li> <li><b>Kingfisher Community Collaborative</b> developed new respite programs for caregivers of children with special needs in rural communities without respite programs. Services provided by the collaborative included a free monthly three-hour respite session in four communities, with plans for expansion in other parts of the state.</li> <li><b>Day Break of Grove's</b> grant funded a new mobile adult day care program that travels to three rural communities. Each week, the program offers care recipients light physical exercise, cognitive enhancement activities, entertainment and a nutritious meal, while providing caregivers uninterrupted respite.</li> <li><b>Daily Living Center's</b> grant expanded adult day respite in four locations supporting overnight respite care for three nights and providing respite gift cards for up to five days of respite at the adult day center.</li> </ul> </li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>Oklahoma Caregiver Coalition's (OCC) mission is to improve the supports and experiences over the lifespan of caregivers through education, advocacy, and access to resources.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>Oklahoma's Aging and Disability Resource Consortium is housed at OKDHS AS. The ADRC priority for this project is the creation of a web portal to serve as the one-stop access point for statewide resources dealing with aging and disability issues and provide extensive reporting capabilities on the information and referrals accessed through the site.</li> </ul>

- The four seed grantees developed written guides for other programs wishing to replicate and sustain similar respite services.

**Objective 2: Expand respite vouchers by linking with organizations serving underserved populations.**

- A grant funded voucher program reached 312 additional families with respite services for caregivers otherwise ineligible for federal and state funded respite services.

**Objective 3: Provide training opportunities for caregivers, long-term care professionals and care recipients.**

- Throughout the grant period, state agency staff presented at conferences and organizations that include family caregivers, care recipients, and professionals working with them including: the Oklahoma Conference on Aging, the Choctaw Nation's Oklahoma Aging Advocacy Leadership Academy, and annual statewide trainings for state Title III Older Americans Act (OAA) providers.
- The seed grantees also provided training at the community level to caregivers on how to access respite vouchers through such venues as health fairs and support group meetings.

**Objective 4: Enhance outreach through collaboration with other agencies/community organizations.**

- Approximately 250 caregivers and 100 service providers were surveyed statewide regarding caregivers' needs, and the highest priority identified was caregivers' need for respite services.
- Grant partners brought together the independently operating Oklahoma Caregiver Coalition, seen as an extension of the previous Oklahoma Respite Resource Network (ORRN), to develop a broad vision encompassing respite care and information, caregiver training, education, outreach and coordination. Parties invited to participate are interested in family caregiver issues and respite for caregivers and included: support groups, AAAs, University of Oklahoma Sooner Success (OUSS), Sunbeam Family Services, 2-1-1 (the state information and referral line), Adult Day Centers, OKDHS Aging and Developmental Disability Services, AARP, VA, tribal groups, and various other private for profit and nonprofit businesses.
- At the community level, seed grantees, familiar with and connected to their local communities, reach out to caregivers directly through: local schools, support groups, OKDHS staff, social organizations, and county coalitions. Grantees used varying outreach techniques including flyers, local newspapers articles, emails, presentations, and word-of-mouth.

**Objective 5: Identify nonprofit organization(s) to sustain vouchers.**

- During the grant period, administration of the Lifespan Respite Grant funded Voucher Program was transferred to OUSS, a well-established nonprofit information and referral resource for Oklahomans with special needs. Targeted outreach to caregivers flourished, and respite vouchers for \$400 were issued to 312 eligible applicants who did not meet eligibility requirements for other existing voucher programs.

**Objective 6: Evaluate programs/disseminate results.**

- Results of caregiver surveys comparing pre-respite to three months post-respite receipt:
  - 93% of Seed Grant Respite care recipients, and 89% of Voucher Respite Care program recipients, reported being "extremely satisfied" or "very satisfied" with the services.
  - 86% of Seed Grant Respite care recipients, and 90% of Voucher Respite Care program recipients, agreed or strongly agreed that the respite helped the caregiver's independence.

**State and Community Partners**

- The Oklahoma Department of Human Services Aging Services (OKDHS AS)
- OKDHS Developmental Disability Services (DDS) is a partner in providing respite vouchers to individuals diagnosed with a developmental disability and administers four Home and Community-Based Medicaid Waivers for recipients eligible to receive respite services
- University of Oklahoma Sooner SUCCESS (OUSS) administers the Lifespan Respite Voucher Program, which is funded by a combination of grant and state funds. OUSS provides respite vouchers to caregivers that do not qualify for any other respite voucher programs
- Oklahoma's Area Agencies on Aging (AAAs)
- Oklahoma Department of Mental Health and Substance Abuse Services
- Sunbeam Family Services whose mission is to provide people of all ages with help, hope, and the opportunity to succeed through Early Childhood, Foster Care, Counseling and Senior Services
- Oklahoma Caregiver Coalition

- 52% of Seed Grant Respite care recipients, and 89% of Voucher Respite Care program recipients, stated that their relationships with other family members improved due to the time relieved from caregiving duties.
- 36% of caregivers receiving Seed Grant Respite care, and 38% of caregivers receiving Voucher Respite Care, reported lower stress levels following use of the respite program.
- 56% of all caregivers receiving respite services indicated that they learned new information and became aware of community resources that could help them in their caregiving role.
- Survey results were shared across state agencies, with the public and public officials, and through the Oklahoma Caregiver Coalition and its network of caregivers and providers.



For more information, contact ARCH at (703) 256-2084 or [jkgagan@archrespite.org](mailto:jkgagan@archrespite.org)



# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Arkansas Division of Aging and Adult Services (DAAS)**

Funding Period: **2014-2017**

**Primary Goal:** The Choices in Living Resource Center – housed within the Aging and Disability Resource Center (ADRC), within DAAS – in partnership with the Arkansas Lifespan Respite Coalition (ALRC) will develop a statewide coordinated lifespan respite system, that builds on infrastructure currently in place, in order to improve awareness of and access to respite information and services among families across age and disability spectrums.

Key Performance Measures	Notable Achievements
<p>ADRC Call Specialists track respite-related calls received, helping to provide streamlined access to respite services. At the end of grant funding, 593 caregivers completed an online respite needs survey. The ALRC plans to seek a legislative study of respite needs to help promote the development of a statewide respite and crisis care system.</p>	<p>The Arkansas Lifespan Respite Coalition worked with legislators in seeking a legislative study regarding respite needs in Arkansas that would help promote the development of a statewide respite and crisis care system.<sup>1</sup></p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Organize state and local partnerships to expand and enhance respite care resources that serve the lifespan.</b></p> <ul style="list-style-type: none"> <li>The grantee and partners developed and disseminated an Arkansas Lifespan Respite Coalition New Membership Letter of Invitation, and held bi-monthly ALRC meetings. Meetings may be attended in-person or by phone in order to include local as well as state partners.</li> <li>During 2017, in three areas of the state, four organizations (two serving aging populations, and two serving persons with disabilities) received mini-grants to provide direct care services for family caregivers using innovative models including yoga for caregivers, family nights out, and vouchers.</li> <li>Read more about the Arkansas Lifespan Respite Coalition [<a href="https://humanservices.arkansas.gov/about-dhs/dpsqa/choices-in-living-resource-center/arkansas-lifespan-respite">https://humanservices.arkansas.gov/about-dhs/dpsqa/choices-in-living-resource-center/arkansas-lifespan-respite</a>].</li> </ul> <p><b>Objective 2: Provide training and recruiting of respite care workers and volunteers.</b></p> <ul style="list-style-type: none"> <li>The grantee contracted with the University of Arkansas for Medical Sciences (UAMS) Schmieding Caregiver Training Program who provided REST Train the Trainer one-day (7.5 hour CEUs approved) and two-day (14 hour CEUs approved) training sessions in 2015 to 9 RNs who led 8 training sessions for more than 100 respite care workers and volunteers.</li> <li>The grantee advertised and provided Volunteer Respite Training statewide including arranging American Sign Language (ASL) interpreters.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Arkansas Lifespan Respite Coalition (ALRC) partnered with the ADRC to oversee and coordinate grant activities.</li> <li>The Arkansas Lifespan Respite Coalition's members represent more than 25 organizations, respite care providers, family caregivers, volunteer advocates, consumers and State agencies.</li> <li>Grant goals and objectives build upon the ALRC's work on their six committees: Membership, Communications (including Website creation and marketing/outreach), Training/Education, Development and Operations, Grant/Funding, and Legislation.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>The Arkansas ADRC and the ALRC are key partners in developing the coordinated</li> </ul>

<sup>1</sup> This goal grew out of the 2013 Arkansas Lifespan Respite Summit.

- The grantee developed a Family Member Information Booklet for the Volunteer Respite Provider.

**Objective 3: Provide online information about available respite and support services.**

- The grantee and partners developed a website for Arkansas Lifespan Respite as part of the DHS Division of Aging and Adult Services state website. Respite services identified around the state are maintained on the Arkansas DHS website and updated as needed. [<https://humanservices.arkansas.gov/about-dhs/dpsqa/choices-in-living-resource-center/available-services-and-resources>].
- The grantee and partners also developed a Respite Provider Form that is included on the website for respite providers who would like to add their names to the locator list.

**Objective 4. Streamline access to respite service through Choices in Living ADRC.**

- The grantee provided in-service training to the Choices in Living Resource Center (ADRC) Call Specialists, and developed resource materials to provide quicker access to callers regarding available respite services.
- Call specialists obtained information regarding 48 additional available respite services for various populations for a total of 78 available respite programs and services throughout the state. Information about these programs and services has been included on the Website (Objective 3).
- Call specialists tracked calls each month regarding: caregivers needing options counseling; caregivers' calls for respite information and referrals; professionals' calls for respite information and referrals; and calls inquiring about the ALRC. More than 3,300 calls were tracked during a two-year period.

**Objective 5. Conduct marketing activities to increase the public's awareness of respite.**

- The grantee developed and distributed a keychain CPR mask kit with logo to promote the ALRC, and designed and purchased a freestanding floor display unit and tablecloth with logo for outreach events, and held Annual Arkansas Lifespan Respite Awareness Events at the State Capitol.
- Among the myriad of public awareness activities were newspaper ads, brochures, flyers and fact sheets, and the grantee participated in 23 conferences and health fairs in 15 cities with respite exhibit booths. Arkansas has continued to print and distribute the Arkansas Lifespan Respite informational brochure through ADRC outreach to Civic Organizations/ Advocacy Groups, Senior Activity Centers, Area Agencies on Aging, Department of Human Services County Offices, Rural Health Clinics, Federally Qualified Health Centers (FQHC) and at conferences statewide.

lifespan respite system and overseeing the grant.

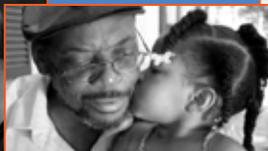
**State and Community Partners**

- The Division of Aging and Adult Services (DAAS) provided staff, outreach and marketing, as well as a graduate student intern from the UALR School of Social Work, and a State General Revenue cash match to support caregiver/respite worker training. The DAAS Information System unit partnered to maintain and update the website.
- Active members of the Arkansas Lifespan Respite Coalition include: Division of Aging and Adult Services; Partners for Inclusive Communities, University of Arkansas; Family to Family; Alzheimer's Arkansas; Self Advocates; Family Caregiver Advocates; National Multiple Sclerosis Society; Senior Health Insurance Information; Arkansas Department of Human Services/Developmental Disabilities Services (DHS/DDS) and Title V Children with Special Health Care Needs Program (CSHCN); Home Instead Senior Care; The Arc of Central Arkansas; Southridge Village Assisted Living; Arkansas Spinal Cord Commission; and Parent Advisory Council, Inc.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Alabama Department of Senior Services (ADSS)**

Funding Period: **2014–2017**

Primary Goal: **To provide a streamlined, coordinated, and person-centered approach to meet the respite care needs of Alabama family caregivers of children and adults regardless of income, race, ethnicity, special needs, or situation.**

Key Performance Measures	Notable Achievements
<p>Data collected on Lifespan Respite includes: phone referrals; email contacts; Facebook and Twitter followers; website visits; respite vouchers issued for direct and emergency respite, and unduplicated counts of families receiving respite. For example, data collected from voucher respite surveys show a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite services versus the percentage before receiving respite services.</p>	<p>State Senate Joint Resolution (SJR) 73 passed in 2015 as a result of a Legislative Resolution drafted by ADSS in partnership with Alabama Lifespan Respite and AARP Alabama office. The resolution established a study committee to evaluate caregivers' needs, make suggestions for policy solutions, and provide a white paper to Governor Robert Bentley and the Legislature for the 2016 Legislative Session.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Enhance and build the Sharing the Care (STC) faith-based initiative.</b></p> <ul style="list-style-type: none"> <li>In 2014, Alabama Respite and the Coalition partnered to conduct a caregiver support survey in faith-based communities. Based on the needs identified in the survey, Alabama Respite developed a toolkit entitled <i>Providing Breaks for Family Caregivers: A Toolkit for Volunteers and Faith</i>.</li> <li>In addition to convening local STC meetings, multiple legislative, caregiver and educational/outreach events were held, and a proposal for funding was submitted to provide voucher respite to the state's Family Caregiver Support Programs, Alabama Cares clients.</li> <li>Share the Care meetings were held in different areas of Alabama throughout the funding period.</li> </ul> <p><b>Objective 2: Utilize new and existing collaborative partners to increase training opportunities.</b></p> <ul style="list-style-type: none"> <li>Numerous training sessions were provided including: Alabama Respite Caregiver Simulations; Helping those Who Care Trainings; Alabama Community Practice for Supporting Families; Caregiving Connections; Alzheimer's associations; home providers training to reduce stress; breakout sessions at conferences; and numerous presentations in communities throughout the state.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Coalition Chairman, Dr. Cary Boswell, a longtime supporter of Alabama Respite, serves as Commissioner of Alabama Department of Rehabilitation Services, a state agency providing a large percentage of the match for the Alabama Lifespan Respite grant.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>The State Project Director of Alabama's ADRC served as lead of the Alabama Lifespan Respite Grant. She supervised the State Coordinator for Alabama Cares and served as an adjunct member of the Coalition.</li> <li>Alabama's state ADRC team provided coordination with caregiver training, ADRC</li> </ul>

## Key Objectives, Activities and Outcomes

- New partnerships were forged with universities; assistive technology initiatives; and a head injury foundation.
- Supported by a Dementia grant award funded by ADSS and administered by Alabama State University Center for Leadership and Public Policy, the Alabama Respite staff partnered with Home Instead Senior Care and ResCare Home Care and provided 1,175 hours of emergency respite services across the state. Alabama Respite staff also provided approximately 725 hours of respite to caregivers who attended the Natural Supports training through their respite voucher program.
- Alabama hosted the National Lifespan Respite Conference in October 2017.

### **Objective 3: Cross-train ARDC Specialists to make resource availability more streamlined, comprehensive, person-centered, and responsive to the needs of caregivers.**

- To improve Alabama's broader No Wrong Door System, Lifespan Respite was added to the Universal Intake Form (UIF), a screening tool used by local ADRC staff at 13 Area Agencies on Aging to ensure seamless access for callers. With their permission, callers are screened and referred to appropriate resources within their local community. Follow-up is provided to ensure the individual's needs were addressed.
- All ADRC Specialists received training collaboratively planned and provided by Alabama Respite staff and Alabama Department of Senior Services.

### **Objective 4: Expand respite to gap populations through mini-grants.**

- Funding announcements were released each year of the grant, and four or five grants were awarded each year to programs representing faith-based organizations, YMCA, Alzheimer's organizations, The Arc, Hospice, Mental Health, Autism organizations and others.

### **Objective 5: Advocate for a formalized Statewide Caregiver sustainability strategic plan to address support services such as education and respite.**

- The Alabama Department of Senior Services and Alabama Lifespan Respite worked collaboratively to develop a white paper, Caregivers in Alabama, based on an evaluation of caregivers' needs, and including policy solutions, for the Governor and Legislature.
- Throughout the grant, data were used to assist in planning, including cataloguing statewide caregiver surveys to determine service gaps with the assistance of faculty from the University of Alabama's Center for Mental Health and Aging.

## Coalition, ADRC and Community Partners

enhancements, and promotion of the Sharing to Care faith-based initiative.

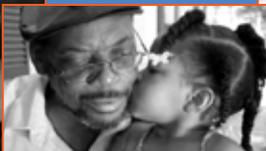
### **State and Community Partners**

- Alabama Lifespan Respite Resource Network (Alabama Respite)
- United Cerebral Palsy of Huntsville and Tennessee Valley (UCP)
- Alabama Lifespan Respite Coalition (the Coalition)
- Aging and Disability Resource Centers (ADRCs)



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Colorado State Unit on Aging**

Funding Period: **2014-2017**

Primary Goal: **Support further integration, scaling and long-term sustainability of Colorado's Lifespan Respite Care Project.**

Key Performance Measures	Notable Achievements
<p>Grantees receiving funding through the Colorado Respite Care Program (CRCP) report the number of hours of respite provided, and the cost per hour. Grantees also administer family caregiver surveys that allow families to document their experiences of how respite services influenced their lives.</p>	<p>The Colorado Respite Coalition received the prestigious Colorado Collaboration Award from the Colorado NonProfit Association in 2015.</p> <p>The CRCP, with the help of Easterseals Colorado and in partnership with the Colorado Respite Coalition, successfully advocated for \$350,000 State General Funds for State Fiscal Year (SFY)16 an increase from \$250,000 in 2015 and \$150,000 in 2014. The funds, which were maintained in the SFY2017 state budget, were designated for respite supports, with the majority distributed as community grants and family respite vouchers across the state and lifespan.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Further strengthen, expand, and enhance respite services to family members.</b></p> <ul style="list-style-type: none"> <li>• CRCP developed a pilot voucher program in 2015, and expanded the program with an expansion grant. Voucher applications and frequently asked questions are translated into Spanish to reach and serve Spanish-speaking populations.</li> <li>• CRCP hosted weekend workshops for families of children and teens with special needs, and a second for adoptive and foster families. The workshops focused on: stress management and self-care; community resources; financial management; and caregiver wellness.</li> <li>• The grantee offered in-home, center-based and recreational respite services through vouchers and the Coming Up for Air family respite weekend.</li> </ul> <p><b>Objective 2: Improve statewide dissemination and coordination of respite care.</b></p> <ul style="list-style-type: none"> <li>• More than 8,000 users visited coloradospitecoalition.org during 2015.</li> <li>• CRCP and its advisory committee developed a pilot voucher program to fund planned and emergency respite that provided more than 2,000 hours of respite to 53 families across the state and across the lifespan during the pilot period.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• The Colorado Respite Coalition (CRC) is a group of 188 caregivers, care recipients, non- and for-profit organizations, and government agencies that meet quarterly.</li> <li>• In addition to serving on the Project's Advisory Committee, the CRC has been actively involved in grant planning, implementation and evaluation including conducting surveys, outreach, awareness and advocacy campaigns; providing services, training, referrals, funding and other supports as needed.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>• Colorado's ADRCs reach 99 percent of the state's population with information, assistance and options counseling. The</li> </ul>

**Objective 3: Provide, supplement, and improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.**

- In 2016, CRCP partnered with 18 agencies to provide caregiver wellness training aimed at supporting caregivers in locating resources, engaging in self-care, and connecting with others to share their experiences. These trainings were offered across Colorado by agencies serving a broad range of ages and conditions. CRCP developed the curriculum from trainings offered by Mental Health America of Colorado and the U.S. Department of Veteran's Affairs, creating a curriculum focused on establishing and maintaining self-care, resources, the importance of respite care and opening a dialogue for caregivers to share their own experiences.
- CRCP partnered with a local author who served as AARP Colorado's caregiving ambassador and co-sponsored training around a variety of caregiving issues including grief, self-care, and embracing the aging process.

**Objective 4: Enhance community understanding and education activities about respite.**

- CRCP reached more than 13,000 individuals in 2015, and more than 14,000 in 2016, through marketing, presentations, coalition meetings and trainings.
- CRCP conducts outreach to Denver Metro Area state department employers and shares tools to support employees who are also caregivers. In addition, CRCP is working to reach employers in the private sector.

**Objective 5: Develop and adopt a statewide respite/caregivers support strategic plan.**

- Colorado policymakers passed HB15-1233, which created a statewide respite task force with broad representation from consumer groups and representatives from several state departments. The task force focused initially on conducting a needs assessment.

**Objective 6: Increase the capabilities of the three newly formed regional respite coalitions.**

- Strategic planning helped support formation of a new regional coalition in the Denver Metropolitan Area.

grantee provided annual training focusing on lifespan respite services and supports to expand ADRCs' options, counselors' knowledge, and resources.

**State and Community Partners**

- Colorado Respite Coalition (CRC)
- Chronic Care Collaborative
- Easterseals Colorado
- In-kind support garnered from Colorado's Health Care for Children with Special Needs Program, National MS Society-Colorado-Wyoming Chapter, Easterseals Colorado, JFK Partners, Diane Mulligan and Associates, and other stakeholders.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Iowa Department of Aging (IDA)**

Funding Period: **2014-2017**

Primary Goal: **Fully integrate a high-quality and sustainable Lifespan Respite program into Iowa's long-term supports and services system so that all Iowans who are eligible for respite services receive them.**

Key Performance Measures	Notable Achievements
<p>Project staff utilized both qualitative and quantitative methods, including statistically validated tools, throughout the project to evaluate progress. The grantee collected data to document increased caregiver knowledge of respite services available in the caregiver's community and ways to easily access those services; increased respite provider knowledge and skills to address the diverse needs of care recipients regardless of their age, disease, or chronic condition; and increased access for caregivers facing emergency situations including support to resolve crises and an individualized plan for on-going respite services and other supports. Expected products include a strategic plan and outreach materials designed for the private sector.</p>	<p>To make and keep their Coalition strong, Iowa used an outside source, Capture Marketing Group, which specializes in association management, advocacy, coalition building and development of best practices for non-profit governance. Significant effort is put into education and marketing opportunities to raise awareness of the Lifespan Respite Coalition, including a Facebook page to raise awareness of respite and caregiving issues, generate interest for annual fall conferences and provide a social media platform for caregivers to ask questions.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Enhance and expand the statewide coordination of respite services by implementing a strategic plan for achieving sustainable, system changes.</b></p> <ul style="list-style-type: none"> <li>• The Coalition engaged in strategic planning sessions that involved completing empathy mapping and an exercise in envisioning exercise that helped the Coalition to define their mission, vision and goals. Based on this planning work, the Coalition decided to investigate both partnering with a current organization to manage the coalition or to start a nonprofit entity for long-term sustainability. The Coalition also completed a Strategic Action Plan to guide their development.</li> <li>• Throughout the grant period, member enrichment and education was an essential component in Coalition meetings. For example, during one Coalition meeting, outside presenters brought information on Iowa's network of Mobility Management and perspective on issues facing working caregivers to recent meetings.</li> <li>• To address sustainability, Coalition leadership led a meeting with agency directors and policy makers to determine the Coalition's future in Lifespan Respite planning and services.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• The Lifespan Respite Coalition consists of twenty provider agencies, three state agencies, and two Lifelong Links™ ADRCs. With facilitation by The Arc of Iowa, the coalition focused on local activities and met monthly to complete the National Respite Network's Lifespan Respite Sustainability Toolkit. The coalition also worked with the Lifespan Respite Coalition Coordinator to organize and synthesize information provided by consumer survey respondents, evaluate impact of training activities, and review crisis respite funding activities in order to develop recommendations for the policy council.</li> </ul>

**Objective 2: Improve respite services by utilizing consumer surveys to identify service gaps and barriers.**

- Regional focus groups were used over the years, and after review the Coalition decided the focus groups did not yield information sufficient to justify the time and effort necessary to conduct them. The Coalition decided to focus instead on statewide conferences in order to provide a forum for a dialogue among stakeholders about current gaps in respite services.

**Objective 3: Improve the quality and consistency of respite services through a training program for providers and caregivers.**

- Annual Care for Caregivers conferences provided education and training opportunities for caregivers, advocates, direct care workers and other professionals.
- To meet the goal of training more direct care workers throughout Iowa, a nationally recognized, evidence-based training program—Powerful Tools for Caregivers— was used to train informal caregivers. The Coalition partnered with Easterseals to offer two sessions of this 6-week training in rural Iowa communities.
- The grant manager stays apprised of issues and policy relating to the direct care workforce with a membership in the Direct Care Worker Advisory Council.

**Objective 4: Improve access to and knowledge of respite services by refining ADRC information/referral system and by outreach to the private sector.**

- Iowa's No Wrong Door [NWD] system, LifeLong Links™, is a comprehensive system that connects Iowans to resources that assist them in attaining independence and full participation in their community. The redesigned LifeLong Links™ website, which went live in 2016, features a user-friendly design for consumers and caregivers to connect with home and community-based services, gain more information on specific topics, and connect with an options counselor for comprehensive assistance in planning for long-term services and supports.

**Objective 5: Reduce caregiver strain by providing crisis respite funds and follow-up services to address long-term needs.**

- The Iowa Department on Aging, the Lifespan Respite Coalition and project subcontractor, Capture Marketing Group, developed procedures for administration of applications, approval and reimbursement for Iowans to access crisis respite funds.
- Approximately 30 families in emergency or crises situations received respite funds during each reporting period.

**Aging and Disability Resource Center (ADRC) Role**

- In addition to expanding services and implementing the No Wrong Door model, ADRCs worked closely with the mental health system during a significant administrative redesign in moving from a county-based system to a regional one. Grant objectives and attendant activities were incorporated into these initiatives so that caregivers could in future easily access the respite services they need in their communities.

**State and Community Partners**

- Iowa Lifespan Respite Coalition
- Iowa Medicaid Enterprises (IME)
- Veteran's Administration
- The Arc of Iowa
- ADRCs
- Iowa Developmental Disabilities Council
- Iowa Department of Health
- AARP
- Alzheimer's Association – Greater Iowa Chapter
- Access for Special Kids (ASK) Resource Center
- One Iowa
- Iowa's community colleges
- State agencies
- Consumer representatives



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Massachusetts Department of Developmental Services (DDS)**

Funding Period: **2014-2017**

Primary Goal: **To ensure that respite is integrated as a critical component of the No Wrong Door approach to long-term services and supports (LTSS) in Massachusetts, and further establish the Massachusetts Lifespan Respite Coalition (MLRC) as a visible source of respite information and supports in Massachusetts.**

Key Performance Measures	Notable Achievements
<p>Massachusetts measures outcomes and products. Outcomes include: 1) increased consumer access to respite services; 2) increased knowledge of best practices in respite care; 3) increased number and diversity of MLRC collaborators; 4) increase in a sustainable pool of respite providers; 5) integration of respite information across state LTSS partners; and 6) improved capacity of employers to recognize and support the role of respite for their employees. Products include 1) a replicable model for states to share best practices on respite mini-grant development and evaluation; 2) a blueprint for statewide respite cross-training for relevant partners; 3) a replicable respite training model; 4) an enhanced provider directory; and 5) training materials for the business community.</p>	<p>The Massachusetts Lifespan Respite Coalition (MLRC) staff conducted “Respite 101” trainings at several Massachusetts companies, assisted company staff in developing a respite/caregiver survey for their employees, and conducted outreach to staff in Human Resources (HR) and Employee Assistance Program (EAP) officers at these companies. MLRC also created an employee survey that they piloted with several local and national corporations and have made this available as a model to be used by other corporations to assess working caregivers’ burden and to further cultivate relationships with the business community.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Provide respite to unserved and underserved populations by distributing a replicable model of “Respite Innovation Mini-Grants” to Massachusetts’ non-profit agencies.</b></p> <ul style="list-style-type: none"> <li>Massachusetts DDS funded five minigrants during the first year of this grant. These mini-grants provided more than 1835 hours of respite services to 174 individuals, supporting both caregivers and care recipients. During the three years of funding, through Respite Innovation Mini-Grants, grantees provided 455 caregivers with 5,553 hours of respite.</li> <li>The lead agency also worked to reach underserved populations through their sponsorship of a REST Train-the-Trainer event in March 2017 at which nine new REST trainers were certified.</li> </ul> <p><b>Objective 2: Expand collaboration with the statewide ADRC network and other LTSS systems in Massachusetts.</b></p> <ul style="list-style-type: none"> <li>The lead agency completed and issued a written evaluation documenting successes and lessons learned from statewide collaboration and included 11 key recommendations. They also developed and refined a successful evaluation model including simple tools that can be</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Massachusetts Lifespan Respite Coalition (MLRC), formed in 2010, was led by a broad range of experts and advocates, including family caregivers, leadership from state agencies, and care providers including representatives from DDS, Massachusetts Executive Office of Elder Affairs, Mass Health Office of Long Term Care, Massachusetts Executive Office of Health and Human Services, National Multiple Sclerosis Society/Greater New England Chapter, Massachusetts Developmental Disabilities Council, Children’s Hospital Boston, and Massachusetts Aging and Disability</li> </ul>

adapted for use by others. These tools were modified for use with two related initiatives – Integrated Memory Cafés and Autism Eats, a communal dining out event for families of children with autism.

**Objective 3: Expand availability of workforce development and respite workforce trainings.**

- The MLRC played an instrumental role in the operation of the Rewarding Work Respite Directory from its inception in 2013. The Directory is a free online resource that allows families to connect with workers who have expressed interest in providing respite as well as personal care assistants (PCA) and other supports to people with disabilities. They also recently launched a job-posting site that allows families to post their own customized job description, which potential workers would then respond to. The Directory currently has a database of over 7000 potential workers.
- The MLRC worked closely with the Students for Higher initiative at Horace Mann Educational Associates (HMEA) as well as its companion program, The Respite Project (TRP).

**Objective 4: Expand and update information on the [www.massrespite.org](http://www.massrespite.org) website, particularly the provider directory section of the website.**

- As part of their work expanding the coalition website, the grantee produced and hosted a Cable Television Show on caregiving and respite reaching 22 Massachusetts communities and several other states.

**Objective 5: Develop and implement a model approach for outreach to the business community on respite issues.**

- MLRC staff conducted “Respite 101” trainings at several Massachusetts companies such as EMC and Raytheon and assisted EMC staff in developing a respite/caregiver survey for their employees. MLRC also conducted outreach to staff in HR and EAP officers at these companies.
- MLRC also created an employee survey that they piloted with several local and national corporations and have made this available as model to be used by other corporations to assess working caregivers’ burden and to further cultivate relationships with the business community.

Resource Consortia. Key coalition members – the National MS Society, ALS Association, Huntington’s Disease Society, Massachusetts Brain Injury Program, Brain Injury Association of Massachusetts, Autism Division at DDS, Autism Support Center at Northeast Arc, Autism Resource Center at Horace Mann Educational Associates, Massachusetts Families Organizing for Change, and Massachusetts Commission on the Status of Grandparents Raising Grandchildren – provided service and advocacy to ensure services are responsive to underserved populations.

**Aging and Disability Resource Center (ADRC) Role**

- Massachusetts’ Balancing Incentive Program (BIP) (awarded in 2014 by the Centers for Medicare and Medicaid Services to promote greater use of home and community-based long-term services and supports) identified the No Wrong Door system as key to ensuring that all individuals may easily access consistent information about options such as respite care. BIP looked to ADRCs as key partners in No Wrong Door information and referral, and MLRC strengthened and enhanced their strong collaboration with the statewide ADRC network in order to position themselves as “Go To” respite care experts in Massachusetts.

**State and Community Partners**

- Massachusetts Lifespan Respite Coalition
- Massachusetts Executive Office of Elder Affairs
- Massachusetts Rehabilitation Commission
- DDS funded Family Support Centers
- Massachusetts Options Counseling Program
- Department of Mental Health
- Personal and Home Care Aide State Training Program (PHCAST)



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Montana Department of Public Health and Human Services (DPHHS), Aging Services Bureau**

Funding Period: **2014-2017**

Primary Goal: **Establish a statewide, coordinated system of easily accessible, quality and affordable lifespan respite care services for Montana's family caregivers.**

Key Performance Measures	Notable Achievements
<p>Performance indicators tracked include: number and demographic diversity of caregivers receiving new respite vouchers; audience reach of public service announcements (PSAs); number of different providers and agencies referring caregivers for respite services; need for respite information as measured by number of caregivers requesting information about respite and applying for new respite vouchers; and increased number of members in the state Lifespan Respite Coalition.</p>	<p>Grant funds were used to establish a new Lifespan Respite Voucher program providing education to caregivers seeking respite, and funding vouchers for 285 caregivers to hire someone they know and trust to provide respite for the family member under their care.</p> <p>The lead agency enhanced the Lifespan Respite Website, with annual updates, to include a searchable database of resources for caregivers including in-home and out-of-home respite providers and educational resources about respite and links to a self-paced caregiver training video.</p> <p>The coalition gained the support of state legislators, and the governor advocated for increased funding to address the unmet need for respite in the state, including in frontier communities.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Develop innovative Lifespan Respite service models that simplify caregiver access to respite.</b></p> <ul style="list-style-type: none"> <li>The lead agency established a clearinghouse with accessible information on respite that became a single point of access for caregivers to call in and have their needs assessed, be linked to available respite services that they may be eligible for, and, if eligible, apply for the grant-funded lifespan respite vouchers that allow caregivers to hire someone they know and trust.</li> </ul> <p><b>Objective 2: Reduce structural barriers that impede the provision of respite.</b></p> <ul style="list-style-type: none"> <li>The Coalition expanded and updated its website, through coordination with the Aging and Disability Resource Centers (ADRCs), creating a statewide resource database of respite providers available to the public. They also created a state map allowing caregivers to easily locate providers serving their county.</li> <li>The grantee added a training module on lifespan respite to the required curriculum for Area Agency on Aging (AAA) and County Council on Aging staff so that they could provide</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Montana Lifespan Respite Coalition, which was created under the previous federal lifespan respite grant, developed Montana's Respite Strategic Plan in 2013. The coalition's four working groups and executive committee served as the planners and engines for many of the grant activities.</li> <li>Developmental Educational Assistance Program (DEAP) coordinated the establishment and administration of the lifespan respite voucher program, the clearinghouse function, and the maintenance and updating of the website.</li> </ul>

education and referrals to respite for clients seeking services as older adults or caregivers of older adults.

**Objective 3: Increase caregiver awareness of the purpose, need for and availability of respite.**

- The coalition wrote and disseminated numerous articles, press releases and caregiver materials in the media, at annual conferences and events, through organizational newsletters and the lifespan respite website.
- Coalition members presented on public television and radio including sharing caregivers' personal stories about the importance of respite breaks to providers.
- A 12-minute video was produced using interviews with caregivers throughout the state explaining the need for and benefits of respite.
- Through the Montana Broadcasters Association, the coalition developed and aired more than 10,000 radio and television PSAs about the importance and availability of the voucher program.
- Through presentations, conferences, and public media, the number of agencies and organizations referring caregivers to respite programming more than doubled during the grant period.

**Objective 4: Develop options for caregiver respite training.**

- The grantee worked with the Montana State University Extension Agency to revive a six-week train the trainer program for caregivers called Powerful Tools for Caregivers.
- The grantee supported access to training for family/primary caregivers through stipends and provision of respite and disseminated a PSA to inform the public about the Powerful Tools for Caregivers program.

**Objective 5: Implement the 2014 state Lifespan Respite sustainability, growth and succession plan.**

- During the grant period, the Lifespan Respite Coalition active membership nearly tripled in size.
- Lifespan Respite coalition members met with and educated state officials about the lifespan respite model and succeeded in gaining the support of a wide group of aging organizations, the Governor's office, and state legislators who advocated for continued resources to support lifespan respite services, including the voucher program.
- The Lifespan Respite Coalition and Money Follows the Person jointly funded the addition of a module of questions about caregiving to the state's 2016 Behavioral Risk Factor Surveillance System (BRFSS). The survey findings from that year documented how prevalent the role of family caregivers is across the state and how often caregivers are providing 40 or more hours of full-time caregiving for friends or family members with a health problem or disability.

**Aging and Disability Resource Center (ADRC) Role**

- The Montana DPHHS' Aging Services Bureau, which coordinates Montana's ADRC network and lies within the Senior and Long-Term Care Division, the lead agency for the grant, also coordinates the ADRC network across the state.
- ADRC's focus had mainly been on services for elders and people with disabilities, but under the Lifespan Respite grant they have evolved into a focal point of information and supports for caregivers looking for respite.

**State and Community Partners**

- Developmental Education Assistance Program (DEAP), a private nonprofit organization serving 17 mostly rural and frontier counties in Eastern Montana, is the longest continuous provider of Lifespan Respite services in the state. DEAP provides direct respite services as well as caregiver and care provider education, links caregivers with respite resources and services, and supports a lifespan respite website. A staff person at DEAP is the point of contact for the statewide Lifespan Respite Coalition.
- The Montana Lifespan Respite Coalition includes staff from the five DPHHS divisions that provide respite care, caregivers, service providers, ADRC staff and other interested parties.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Nebraska Department of Health and Human Services (DHHS)**

Funding Period: **2014-2017**

**Primary Goals:** To enhance the utility of eLifespan Respite (a secure online data management site and a workstation site for the Nebraska Lifespan Respite Network) and the Nebraska Resource and Referral System website ([nrrs.ne.gov/respite](http://nrrs.ne.gov/respite)) so they are utilized by multiple state and local programs that fund or assist family caregivers in accessing lifespan respite services.

To engage employers in increasing awareness of respite resources for employees as caregivers.

Key Performance Measures	Notable Achievements
<p>The lead agency collects lifespan respite data including: family caregiver outcomes, satisfaction with respite, respite utilization, number of providers trained, referrals to respite, provider matches to family caregiver needs, process measures of increased capacity of the eLifespan Respite database, resources added to Nebraska Resource and Referral System (NRRS)/respite website and access to Nebraska Lifespan Respite Network screened providers, and utilization of the Lifespan Respite Subsidy program.</p>	<p>Nebraska DHHS enhanced the cross-system statewide respite infrastructure supported by a system framework with extensive capacity for online data entry and analysis. The framework assists in the evaluation of Nebraska’s Lifespan Respite Network overall, as well as outcomes for family caregivers and respite providers who access the state’s diverse lifespan respite resources. A 3-year evaluation gathered comprehensive information about respite services in Nebraska and how those services were both provided and received. DHHS provided train-the-trainer events and several provider trainings (using the Respite Education and Support Tools [REST] model), added agricultural/equine assisted respite activities programming, and piloted a college-based respite-focused student service learning certificate program to increase the number of trained respite providers. The lead agency also enhanced the NRRS website to simplify provider enrollment and facilitate information on respite training and continuing education. The lead agency created a structured process and materials to engage businesses and help them educate their caregiver employees about what respite is and the lifespan respite resources available to them.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1. Utilize technology and make resources available to ensure greater accessibility of respite providers.</b></p> <ul style="list-style-type: none"> <li>The lead agency used targeted social media platforms (including Facebook, Pinterest, Instagram and Twitter) to increase awareness about and how to access respite.</li> <li>The lead agency added respite resources to the <a href="http://nrrs.ne.gov/respite">nrrs.ne.gov/respite</a> website, including essential provider forms, recognition for REST trained and Nebraska Lifespan Respite Network screened providers, updates to improve the mapping system that helps family</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Nebraska Caregiver Coalition is a statewide volunteer coalition that works closely with DHHS, AARP Nebraska Chapter and representatives from governmental, nonprofit and for-profit agencies, including faith-based</li> </ul>

caregivers locate a qualified respite provider near to them with skills to match loved ones' unique needs, employer engagement information, and family caregiver resources.

- The lead agency implemented a text messaging outreach effort to respite providers and a similar text outreach effort to families receiving Lifespan Respite Subsidy funding.
- The lead agency collaborated across programs within DHHS and the Service Learning curriculum to encourage use of the online respite provider orientation and to share respite providers across the agency's diverse respite funding sources.
- The lead agency integrated stories and quotes from family caregivers into the extensive lifespan respite public awareness/outreach efforts.
- The lead agency created a user-friendly online provider enrollment and screening process and a Provider Portal that houses resources for respite providers including a Provider Calendar to share information on a range of trainings available as webinars or on-site.
- The lead agency held multiple REST train-the-trainer events with trainees conducting REST trainings across the state.
- Agency partners developed and implemented a Respite-Focused Student Learning Service program for college students at the University of Nebraska Medical Center in Omaha and incorporated the project into an existing course taught at a college in the Eastern region of the state.
- Funds were leveraged for equine assisted respite activities with train-the-trainer programming for statewide replication of a sustainable business model.

**Objective 2: Document the outcomes and effectiveness of the state and local lifespan respite programs.**

- The lead agency used data from family caregiver and provider surveys, evaluation and other sources to evaluate network activities and document caregiver satisfaction with respite used, impacts of respite on family caregiver health and mental health, and factors affecting respite use and accessibility.
- The lead agency developed a Data Dashboard that provides access to current and historical respite data for each of the six regions of the Nebraska Lifespan Respite Network.

**Objective 3: Engage businesses in increasing awareness of employee caregiver issues, the benefits of respite care, and access to resources available through the Nebraska Lifespan Respite Network.**

- DHHS provided training, technical assistance, structured presentations, and flyers for local Lifespan Respite Coordinators to help them engage employers.
- Local Lifespan Respite Coordinators joined chapters of business and nonprofit networking associations to help establish connections with area businesses and key human resource personnel.
- Informational materials on Nebraska Lifespan Respite Network resource and caregiver issues were disseminated to all Chambers of Commerce, Walmart, and McDonalds managers in the state.
- Outreach resulted in several businesses providing referrals to the Lifespan Respite Subsidy Program and the placement of resources or links to the state respite website (NRRS) on the businesses' websites.
- University of Nebraska Medical Center and Nebraska Medicine both integrated information on respite resources into their employee new hire orientation process.

organizations, advocacy groups and family caregivers to support the ongoing development and improvement of Nebraska's Lifespan Respite System.

- The NE Caregiver Coalition focuses on education, identifying system gaps and policy changes needed to address those gaps as well as identifying solutions to barriers family caregivers face in finding and using respite services. The coalition involves many family caregivers and serves as a vehicle for family caregiver input into respite solutions and the Lifespan Respite System to caregivers, providers and policy makers.

**Aging and Disability Resource Center (ADRC) Role**

- The ADRC Nebraska Demonstration Project was established by the Nebraska Legislature in 2015 under LB 320. The purpose is to evaluate the feasibility of establishing resource centers statewide to provide information about long-term services and supports (LTSS) available in the home and community for older Nebraskans, persons with disabilities, family caregivers, and persons who request information or assistance on behalf of others. The goal is to assist eligible individuals to access the most appropriate public and private resources to meet their LTSS needs, including respite.

**State and Community Partners**

- The Nebraska Department of Health and Human Services (DHHS) oversees the state-funded Lifespan Respite Program, which provides lifespan respite services, a state-funded lifespan respite subsidy program, supports to family caregivers caring for loved ones of all disability populations and is tasked with building systems of lifespan respite care across the state. The state agency oversees six local respite networks and collaborates with the NE Caregiver Coalition to: identify, coordinate and develop community resources for respite; conduct public awareness about respite; organize family

## Key Objectives, Activities and Outcomes

- DHHS created a statewide Business Outreach Record template for local Lifespan Respite Coordinators to enter information on engagement of local businesses. Summary results are posted online in the eLifespan Respite system's Employer Engagement portal (<http://support.answers4families.org/node/1133/webform-results>).

## Coalition, ADRC and Community Partners

caregiver and provider trainings; recruit and screen paid and volunteer respite providers; and help caregivers identify respite needs and link them to available providers and payment resources. Since inception of this grant, they also engage businesses to increase awareness of respite resources among employees as caregivers targeting workplace wellness, employee assistance programs, human resource professionals and trade organizations. The state Lifespan Respite program also created and manages the eLifespan Respite secure web-based data collection and reporting system and a 24-hour toll-free helpline.

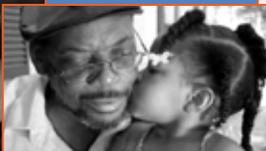
- The Nebraska Special Needs Ministry Network provides a collaborative community where participants meet regularly to discuss the issues, ideas, needs, and solutions unique to special needs ministry and respite delivery.
- The University of Nebraska's Medical Center Munroe–Meyer Institute actively engaged in respite evaluation, public dissemination of information on the grantees' innovative Employer Engagement Initiative and Respite-Focused Service Learning Program for college students wishing to become certified in home-based respite care providers.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)



## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Nevada Department of Health and Human Services, Aging and Disability Services Division (ADSD)**

Funding Period: **2014-2017**

Primary Goal: **Build a sustainable respite system for the lifespan that empowers caregivers to seek respite through both public and private resources.**

Key Performance Measures	Notable Achievements
<p>Outcomes identified by the grantee include: number of family caregivers able to access respite outside of public resources; number of caregivers receiving Options Counseling; percent of caregivers reporting improved quality of life as a result of receiving BRI Care Consultation services; percent increase in the number of respite providers, paid or volunteer based, serving consumers age 18–59 as measured by data reported by the Lifespan Respite Coalition; and percent increase in the number of consumers in rural areas who are able to access respite services based on data available in the current client management system, SAMS.</p>	<p>After training from the Rosalynn Carter Institute for Caregiving, the Benjamin Rose Institute (BRI) Care Consultation program was launched and embedded through a partnership with Nevada Care Connection, Nevada’s Aging and Disability Resource Center brand. Of participants using Care Consultation, 76 percent reported increased capacity to provide care, and 78 percent reported decreased anxiety as a result of the support provided by Care Consultants.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Educate and support family caregivers in accessing services through Nevada’s Care Connection, Aging and Disability Resource Center program (i.e. implementation of Benjamin Rose Institute [BRI] Care Consultation services).</b></p> <ul style="list-style-type: none"> <li>Rosalynn Carter Institute for Caregiving provided evidence-based BRI Care Consultation training and support to Nevada’s Care Consultant at Nevada Senior Services at the beginning of grant funding. Nevada Senior Services, the community partner selected to provide the RCI/BRI Care Consultation program delivery worked to expand Nevada’s existing toolbox of available evidence-based services statewide.</li> <li>The BRI Care Consultation program was launched and embedded through a partnership with Nevada Care Connection, Nevada’s Aging and Disability Resource Center brand. Of participants using Care Consultation, 76 percent reported increased capacity to provide care, and 78 percent reported decreased anxiety as a result of the support provided by Care Consultants.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b> (None noted)</p> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>As key partners in the Lifespan Respite grant, Aging and Disability Resource Centers (ADRCs) administered emergency respite vouchers to family caregivers for persons ages 18 to 59 with disabilities – a gap population.</li> </ul>

**Objective 2: Create a sustainable workforce of respite providers across the lifespan through increased volunteer opportunities and state general fund support, working with existing respite organizations as well as faith-based organizations.**

- Nevada Aging and Disability Services Division (ADSD), with project partners, implemented the Respite Education and Support Tools (REST) training program to standardize training for respite providers. In total, 27 organizations across Nevada participated in REST training. Nevada certified three master trainers who will continue offering training to new trainers beyond the grant. Through these 27 organizations, 53 trainers were trained.
- Through this initiative, 426 Companions received training and are providing respite throughout the state. Prior to the implementation of REST, there was no formal training mechanism for formal, paid respite providers or volunteer-based respite providers in Nevada.

**Objective 3: Increase public awareness of respite through targeted outreach in local communities. Outreach ads, utilizing the Volunteer Collaborative Got an Hour campaign, will be a call to action to family, friends and neighbors of caregivers to offer assistance to a caregiver.**

- ADSD created opportunities for statewide outreach and marketing that encouraged caregivers to seek respite services, and encouraged fellow Nevadans to “Take Notice, Lend a Hand.”
- Nevada ADSD built upon previous grant efforts to expand information available on the Nevada Care Connection website. Previous grants provided an opportunity for ADSD to develop a lifespan respite website which included a definition of respite, training for providers to talk to caregivers about respite and information on types of respite. Under this project, ADSD added a caregiver support section “Nevada Cares for Caregivers” accessible from the home page, and is also incorporated into various other sub-sites within the website. This expanded section helps caregivers recognize they are a caregiver, access the original information regarding respite services, share stories from other caregivers, and it provides information about various caregiver support programs available in Nevada. This website was also used as a basis for a statewide outreach campaign.

**Objective 4: Provide opportunities to family caregivers for the ages 18–59 gap population with disabilities to obtain emergency respite services in order to prevent caregiver burnout.**

- The ADRC Administrators worked to determine procedures for having the ADRC administer emergency respite vouchers to family caregivers for the individuals between the ages of 18 to 59 (gap population). Discussion occurred about qualifications for the program, how much each voucher should be worth, and who will house and distribute the funds as initial steps toward ADSD’s goal of providing opportunities to family caregivers to obtain emergency respite services in order to prevent caregiver burnout.

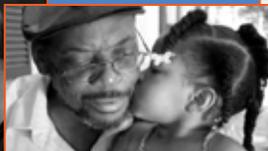
**State and Community Partners**

- Marklund Children’s Home – Respite Education and Support Tools (REST)
- Rosalynn Carter Institute (RCI)
- Benjamin Rose Institute (BRI)
- Nevada Senior Services
- Aging and Disability Resource Centers (ADRCs)
- Nevadans for the Common Good
- No Wrong Door/Access to Healthcare Network



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **New York State Office for the Aging (NYSOFA)**

Funding Period: **2014-2017**

Primary Goal: **Continue building a coordinated and sustainable state Lifespan Respite Program that expands access to respite and is fully integrated into New York State's Long Term Services and Supports System.**

Key Performance Measures	Notable Achievements
<p>Data collected on lifespan respite includes: number of trained volunteers providing respite to caregivers and families; and number of caregivers using NY Connects (a state funded information and resource initiative). Data on utilization of consumer-directed respite voucher model under the Older Americans Act (OAA) Title III-E program will be collected in future.</p>	<p>Lifespan Respite Program partners established a train-the-trainer program, using an evidence-model of respite provider training, to expand the workforce of volunteer respite providers across the state. Key partners also collaborated with other state agencies to establish Medicaid funding for the Caregiver Support Program as part of New York State's Balancing Incentive Program (BIP) demonstration. This funding was provided to expand availability of services and supports to caregivers across the lifespan caring for Medicaid eligible individuals of all ages and disabilities. Respite services listings have been updated and caregiver-specific activities associated with respite services listings have been added to the NY Connects Resource Directory.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Expand available respite by a workforce development initiative and protocols for respite voucher programs.</b></p> <ul style="list-style-type: none"> <li>In 2016, the New York State Caregiving and Respite Coalition (NYSCRC) Director and a Lifespan of Greater Rochester partner trained to become Master Trainers for the Respite Education and Support Tools (REST) model. This enabled them to provide training to staff of organizations across the state, who in turn would provide training to volunteer respite providers.</li> <li>A mini-grant/application process was undertaken, and in September 2016 nine organizations received mini-grants to receive REST training and develop/expand volunteer respite programs: the Autism Society of the Greater Capital Region, Baker Memorial United Methodist Church, Caregiver Resource Center, Steuben County Faith In Action Program, Home Away from Home Drop-In Respite, Kinship Caregiver Program's Leadership Training Institute, Mercy Care for the Adirondacks, United Cerebral Palsy Association of the North County, and Parma Baptist Community Church. By end of 2017, 3 master trainers, 100 trainers, and 100 companion volunteers were trained in REST in 26 counties.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>New York State Caregiving and Respite Coalition (NYSCRC), hosted by Lifespan of Greater Rochester, was established through the original federal Lifespan Respite grant and has become a valuable, well known caregiving and respite resource across the state.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>New York State's ADRC/No Wrong Door (NWD), New York Connects, has primary responsibility for maintaining the NY Connects Resource Directory of</li> </ul>

- During 2017, three Caregiver Simulation sessions were held and attended by 45 to 60 persons at each session. Participants received training that enhanced understanding of caregiving responsibilities and stress; knowledge of community services; day-to-day caregiver experiences; and how the aging population impacts the need for services.

**Objective 2: Integrate the Lifespan Respite Program into the State Long Term Services and Supports System (LTSS) and into the NY Connects Resource Directory database.**

- NYSOFA team members worked closely with other state agencies in developing the state plan for New York's Medicaid LTSS Balancing Incentive Program (BIP), and specifically the BIP Caregiver Support Program which was launched in 2016, serving individuals in 39 counties across the state. This program, which utilized Medicaid funds for respite and support options for caregivers across the lifespan who are caring for individuals of all ages and disabilities and are Medicaid eligible, coordinated closely with ongoing programming administered by NYSOFA.
- NYSCRC updated its website <http://www.nyscrg.org/> during 2017 and continued to build content and create a go-to place for information tailored to informal caregivers and the professionals who serve them.

**Objective 3: Develop a Statewide Action Plan for Lifespan Respite Care sustainability.**

- The NYSCRC Director conducted extensive outreach to build connections within the caregiving network. During the first half of the grant, the NYSCRC had reached out to more than 1,000 aging and disability groups across the state to invite interested groups and individuals to participate in the continuing development of the NY Lifespan Respite Program. An advisory committee consisting of 22 members was established in 2016 including stakeholders from the fields of aging, Alzheimer's disease, mental health, developmental disability, and child and family services sectors. The committee efforts focus on advocacy, website updates and sustainability of the statewide Lifespan Respite Program.
- NYSCRC also distributes monthly newsletters to approximately 800 individuals and organizations, hosts a website, and holds an annual conference that brings together state and local agencies, family caregivers, and the professionals who support them.

community-based long-term services and supports.

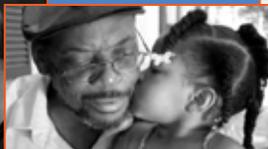
**State and Community Partners**

- New York State Office for the Aging (NYSOFA) administers the federal Older Americans Act and OAA Title III-E, NY Connects (a state funded information and resource initiative), and other state-funded long-term services and supports. NYSOFA is also the lead agency for the NY State Family Caregiver Council and is co-chair of the New York State Coordinating Council for the Services Related to Alzheimer's disease and Other Dementias. In addition to housing the Project Coordinator, an internal team that includes NYSOFA's executive management and staff from all agency divisions is involved in all aspects of building New York's Lifespan Respite Program.
- NY Connects
- New York State Caregiving and Respite Coalition
- Monroe County Office for the Aging and Adult Services (MCOFA). In addition to being the administering fiscal agent for the federal grant, the director of MCOFA participates in the NY Lifespan Respite Project core team and acts as the liaison to the New York State Association of Area Agencies on Aging to actively assure coordination with the local AAAs.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **North Carolina Division of Aging and Adult Services (DAAS)**

Funding Period: **2014-2017**

Primary Goal: **Ensure that family caregivers across the lifespan have access to high quality, coordinated, and person/family-centered respite resources in the State of North Carolina.**

Key Performance Measures	Notable Achievements
<p>Data collected on lifespan respite includes: evaluation of Care Management/Care Planning Tools; caregiver satisfaction; and ability to continue to provide care for their family members as a result of using lifespan respite services. North Carolina also collects qualitative data documenting their planning process, and primary data in the form of letters from caregivers about their respite experiences.</p>	<p>The Lifespan Respite Care State Advisory Team includes small work groups that meet to flesh out initiatives to propose to the large group. The Respite Barriers Strategic Plan Workgroup identified barriers that keep people from getting or using respite as intended. The workgroup developed a template to communicate basic information on each publicly funded respite option in North Carolina. The template briefly describes each option as well as information on eligibility, cost, how to apply, and who to contact for additional information. The template also identifies barriers in policy or process that keep caregivers from accessing or using respite service options.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Further efforts to embed a caregiver and respite focus in the state's Long-Term Services and Supports (LTSS) systems through ongoing partnerships with ADRCs, Money Follows the Person, community-based Medicaid and social services, and critical programs.</b></p> <ul style="list-style-type: none"> <li>• With extensive stakeholder input, the Lifespan Respite Advisory Team prepared and disseminated a five year strategic plan and worked on implementing recommendations of the plan, including: <ul style="list-style-type: none"> <li>▪ Development of a shared definition of respite to be endorsed by multiple organizations including the NCRCC and the Lifespan Respite State Advisory Team, to be rolled out to other interested networks and organizations.</li> <li>▪ Development of new fact sheets on each publicly funded respite option in North Carolina summarizing information on eligibility, cost, how to apply, who to contact for additional information and barriers in policy or process that hinder access or use of the service option as intended. These fact sheets are designed to be shared with caregivers, the entities which fund respite services, and agencies that work with caregivers and need information to help them find the respite services that best meet their circumstances.</li> </ul> </li> <li>• With funds from the Money Follows the Person Rebalancing Fund, the Lifespan Respite project contracted for a "Care Management Quality Initiative" to improve the quality and consistency of care planning and assessment used in the State's Project C.A.R.E. (Caregiver</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• North Carolina Respite Care Coalition (NCRCC) is a 501(c)3 nonprofit organization that supports a network of parents, family caregivers, professionals in the field of respite care and others who have an investment in family support services. Its mission is: "to promote and support a statewide quality intergenerational respite care system." The NCRCC is the key partner with the DAAS in the development and implementation of the Lifespan Respite five-year strategic plan. (Note: North Carolina's respite coalition ceased to operate functionally in 2017).</li> </ul>

Alternatives to Running on Empty), a program for caregivers of persons diagnosed with dementia. This initiative developed and will evaluate new care planning/care management tools (a caregiver assessment tool, caregiver action plan/care plan and family consultant checklist) to assess the effect on caregivers' satisfaction and ability to continue to provide care for their family members.

**Objective 2: Increase capacity of the business community to support and appropriately assist employed caregivers.**

- The grantee disseminated a resource packet on caregiver needs and marketed web-based training modules to Employee Assistance Program staff in the private sector and health and human service organizations. The module, previously developed for the state's certified options counselors, is designed to provide these professionals an understanding of caregiver demographics and needs, barriers to caregivers utilizing services and how to overcome them, and how to better recognize, assess and support caregivers in using informal and formal respite services in helpful and cost-effective ways.

**Objective 3: Research and develop new strategies for state-level partnerships and sustainability of the state's respite care coalition.**

- The NCRCC more than doubled its membership size during the project period.
- The NCRCC developed and implemented a business plan for sustainability of the coalition and created leadership development opportunities for staff and members.
- The NCRCC Board determined that to best accomplish its mission, the NCRCC would focus on organizational development and advocacy to strengthen and expand lifespan respite services for families throughout the lifespan.

**Aging and Disability Resource Center (ADRC) Role**

- DAAS, lead agency for North Carolina's Lifespan Respite Care Program, provides oversight for all of grant activities. DAAS works closely with the state's Area Agencies on Aging (AAAs), 100 county Departments of Social Services and more than 400 local providers administering and implementing programs funded by the Older Americans Act.
- The state's 16 AAAs play a key role in the respite care system in the state. Each AAA is staffed with a full-time family caregiver resource specialist who assists caregivers in locating respite services.

**State and Community Partners**

- Division of Aging and Adult Services, North Carolina Department of Health and Human Services (NCDHHS)
- North Carolina Respite Care Coalition
- Area Agencies on Aging
- Division of Medical Assistance (DMA) manages the state Medicaid Program and has been a key collaborator with DAAS Lifespan Respite Project staff and the Lifespan Respite Project's Advisory Team. During the last three-year grant, DMA's Money Follows the Person Rebalancing Fund began supporting Family Caregiver-to-Caregiver Peer Support grantees across the state, which remained active throughout the three-year grant period.
- University of North Carolina at Chapel Hill, Center for Aging and Educational Resources (CARES) shared expertise in curriculum development, instructional design and e-learning for human services professionals. Under North Carolina's previous Lifespan Respite grant, UNC CARES helped design web-based training modules for health and human services professionals who provide information and referral options counseling to family caregivers. Under this grant, UNC CARES helped DAAS modify the modules for their roll out to staff in the private sector.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Rhode Island Department of Human Services/Division of Elderly Affairs (DEA)**

Funding Period: **2014-2017**

Primary Goal: **Integrate, bring to scale, and achieve long-term sustainability of Lifespan Respite Services in the state.**

Key Performance Measures	Notable Achievements
<p>This project developed a formal evaluation plan to track outputs, outcomes, and the effectiveness of interventions including: number of nursing students providing respite services; number of families served by the newly trained workforce; the number of individuals receiving information and education on the Caregiver Alliance; the number of families receiving subsidized respite care; and caregiver and nursing student satisfaction.</p>	<p>University of Rhode Island College of Nursing reports positive experiences by both nursing students and caregivers. Interested students provided respite during winter break, beyond course expectations, to ensure continuity for families between school semesters. Caregivers verbally expressed happiness about and appreciation of respite provided and rated them as professional, knowledgeable and caring. Students verbally expressed enjoyment and self-satisfaction with providing respite. One family's positive connection with a student led to a paid respite position at the completion of the clinical placement.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Implement two new sustainable workforce development initiatives targeting nursing students, one of which will recruit nursing students as volunteers and/or as part of clinical coursework, and a second which will offer respite services as a clinical placement option for course credit.</b></p> <ul style="list-style-type: none"> <li>The Student Respite Initiative launched spring semester, 2016, during which five nursing students provided respite services to five families. During fall semester, 2016, 11 students provided respite services. During spring semester, 2017, 10 families received respite from 16 students. Each student provided between 10 and 56 hours of respite. Overall, 53 nursing students provided respite services to more than 20 families.</li> <li>Rhode Island College of Nursing uses a process to match student nurses with caregivers of children with special needs, with families of adults and families of older adults according to their needs.</li> </ul> <p><b>Objective 2: Improve awareness about respite services, and access to respite services, through the Rhode Island Aging and Disability Resource Center (ADRC).</b></p> <ul style="list-style-type: none"> <li>Create one or more strategically located webpages and links, and engage partners in outreach activities.             <ul style="list-style-type: none"> <li>The Department of Elderly Affairs (DEA) and Healthcentric Advisors, a nonprofit healthcare quality improvement organization, worked on a DEA website with a Caregivers section that was finalized and supported by Rhode Island's 2017 Lifespan Respite Grant.</li> </ul> </li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Caregiver Alliance of Rhode Island (the Alliance), the state's respite coalition, was an informal group comprised of disparate agencies, organizations and individuals prior to funding of this grant. With funding, and membership of the state and community partners listed below as well as service provider agencies, family caregivers, and disability related organizations, the Alliance became a formal non-profit organization and developed tools to effectively advocate and be a resource for family caregivers and respite providers.</li> </ul>

## Key Objectives, Activities and Outcomes

- Healthcentric Advisors provided outreach to the medical communities and to other organizations as directed by DEA, including providing materials at medical and at caregiver events, target emails, newsletters and phone contact.
- Outreach was accomplished by United Way of Rhode Island (UWRI) at 235 events in 35 locations across Rhode Island including clinics, food centers, community action programs, senior centers, church gatherings, festivals and community advocacy groups. During these events 315 caregivers received assistance, and 400 caregiver booklets were distributed.
- The POINT receives an average of 600 calls per month from caregivers requesting services and information on the following topics: Medicare/Medicaid, nursing homes and assisted living facilities; HealthSource and other long term care, transportation, and financial assistance. POINT staff trained on available services totaled 147 from January 2015 through August 2017.
- Formalize and strengthen the Caregiver Alliance of Rhode Island as an advocate for caregivers.
  - By-laws for the Family Caregiver Alliance were completed and approved by UWRI as part of their existing infrastructure, thereby formally incorporating the Alliance as a non-profit under UWRI and allowing the Alliance to continue its activities after the grant cycle ended.
- Continue funding the *CareBreaks* respite program that was implemented under the previous Lifespan Respite Grant.
  - Healthcentric Advisors and project partners updated outreach materials and respite applications to simplify and clarify the process for key community stakeholders, and to create a less burdensome process for caregivers.
  - During the funding period, Catholic Social Services served 190 families through their *Carebreaks* respite program.

## Coalition, ADRC and Community Partners

### Aging and Disability Resource Center (ADRC) Role

- The Rhode Island ADRC has been a partner in the Lifespan Respite project since the project's inception.
- The POINT, a key operating partner within the Rhode Island ADRC system, worked to raise awareness and promote access to direct care services for family caregivers.

### State and Community Partners

- Caregiver Alliance of Rhode Island (the Alliance)
- United Way of Rhode Island (UWRI)
- University of Rhode Island College of Nursing
- Catholic Charities of the Diocese of Providence
- CEDARR Family Centers
- DEA's respite program, *CareBreaks*



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **South Carolina Lieutenant Governor's Office on Aging (LGOA)**

Funding Period: **2014-2017**

Primary Goal: **To further integrate respite services into South Carolina's long-term services and supports as part of a coordinated and sustainable lifespan respite system.**

Key Performance Measures	Notable Achievements
<p>Performance indicators tracked include: increased engagement of stakeholders at the state and regional level, increased respite training opportunities at Institutes of Higher Education (IHEs); increased respite service delivery and sources of respite funding; and integration of caregiver supports into the long-term services and supports system.</p>	<p>South Carolina developed sustainable state and regional advisory committees that provided extensive education and outreach to a variety of stakeholders (including families, caregivers, health and social professionals, state officials, the faith community and business leaders) on the importance of respite and ways to expand respite provider capacity at the local level. The lead agency successfully advocated for the creation of a one million dollar line item in South Carolina's state budget for lifespan respite vouchers and a process for disseminating those vouchers to traditionally underserved caregivers.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Enhance lifespan respite services at state and local levels by increasing outreach and broadening stakeholder engagement, and re-evaluating and updating the Lifespan Respite State Plan through state and regional advisory committees to realize sustainability of the coordinated lifespan respite program.</b></p> <ul style="list-style-type: none"> <li>The Lieutenant Governor's Office on Aging (LGOA) and key partners expanded and sustained an active State Committee on Respite (SCOR) and met in full committee and subcommittees to address gaps and obstacles to respite access; to increase education and outreach; to implement policy and legislation; and to develop increased respite provider capacity across the state.</li> <li>Lead grant partners fostered two sustained regional advisory councils that are championing lifespan respite in the Upstate and the Low Country. Each regional council built local partnerships and conducts public events and other outreach to provide information about respite and connect family caregivers across the lifespan with respite resources in their area.</li> <li>The LGOA and partners completed a comprehensive Lifespan Respite State Plan 2018, presented in February 2018 at a news conference at the State Capitol on Respite Awareness Day.</li> <li>The LGOA and partners conducted extensive in-person, media, and online outreach and education to increase public awareness about respite and the needs of caregivers.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The South Carolina Respite Coalition (SCRC), a statewide non-profit organization founded in 1999, co-facilitates the work of the SCOR, and leads the development and support for the Regional Advisory Committees and the work with community and faith-based organizations. The SCRC also hosts the dedicated respite website.</li> <li>In coordination with the ADRCs/Family Connection of South Carolina (FCSP) as part of the state's Coordinated Lifespan Respite System, the SCRC manages and operates the respite voucher program for caregivers of children and adults with disabilities and works with the state Long Term Care Task Force and IHEs to build respite provider recruitment and training opportunities.</li> </ul>

- The LGOA and partners increased engagement of organizations and families as champions for and educators about respite through one-on-one meetings and presentations at conferences of organizations, business groups, and task forces concerned with the needs of older adults, persons with mental health challenges, Alzheimer's and long-term care health and related services.

**Objective 2: Increase integration by building local networks to recruit and train respite providers, including volunteers, by working through the Regional Councils and Community-based organizations, including faith communities and other forums.**

- The LGOA and partners conducted workshops, presentations and exhibits on respite and how to build respite locally at numerous conferences of caregivers and professionals working with caregivers needing respite, including Family Connections, the Faith Community Health Nurses, the Faith Community Health Ministry Association, case managers working with the older adults and individuals with autism, the Caregiver Leadership Conference, and local Caregiver coalitions.
- The South Carolina Respite Coalition (SCRC) provided technical assistance to individual churches about how faith communities can develop or expand respite services, including adult part-day programs.
- Based on advocacy and leadership of the Upstate Regional Advisory Council, a new adult part-day social model respite program site opened in Seneca in August 2016.

**Objective 3: Initiate respite recruitment and training opportunities through South Carolina's Institutions of Higher Education (IHEs), by working through the Long-Term Care (LTC) Taskforce Development work group and directly with those IHEs.**

- The LGOA and partners successfully integrated recommendations in the 2015 state Long-Term Care Taskforce report on the need to engage IHEs in respite provider training.
- The LGOA and partners worked with Midlands Technical College to educate students on how to become an in-home respite provider and began discussions with college leaders on development of a Respite Caregiver course or certificate program.

**Objective 4: Fill gaps and increase availability of respite by expanding vouchers across the lifespan, sustain and increase coordination with other voucher programs.**

- In addition to maintaining funding for respite vouchers for individuals caring for someone with Alzheimer's or dementia, respite champions engaged through the grant work successfully advocated in 2015 for \$1 million for respite vouchers as a recurring line item in the LGOA budget for lifespan respite bringing the total to about \$2 million. By state FY 17–18, with advocacy from respite champions and coalitions built across the state, the total appropriation was further increased to \$2.4 million in recurring respite funds.
- Information on vouchers administered through different organizations are kept in a common database system (AIM) to promote coordination and exchange of information across the providers and programs and thus prevent duplication of effort, fill gaps, and ensure more families can be served.

**Objective 5: Sustain efforts and further integrate respite into the state's Long-Term Services and Support System (LTSS) across agencies and the lifespan.**

- Lead grant partners served on the South Carolina Institute of Medicine and Public Health (IMPH) Long-Term Care Task Force and succeeded in integrating lifespan respite into the

**Aging and Disability Resource Center (ADRC) Role**

- The ADRCs are partners in the state's Coordinated Lifespan Respite System.

**State and Community Partners**

- Family Connection of South Carolina (FCSC), founded by parents of children with special needs, provides direct parent-to-parent support through a network of families and area offices across the state. FCSC actively participates in the SCOR and is the lynchpin for outreach and engagement of caregivers of children.
- Aging and Disability Resource Centers
- South Carolina Respite Coalition

report's recommendations for long-term care workforce development and as a significant and less costly mechanism for supporting family caregivers. They continue to work with IMPH to ensure continued coordination between the Lifespan Respite and long-term care planning processes in the state.

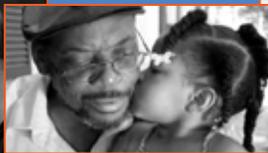
- Representatives from the Lifespan respite partner organizations serve on the state's senior advocacy group called "Silver Haired Legislature," which in the 2017–2018 session made respite services its top legislative priority.
- SCRC is working with the South Carolina Department of Health and Human Services (SCDHHS) on the planning and implementation of a system of care for serving the state's youth with severe behavioral health conditions.
- Lead partner groups worked to incorporate short-term respite services as a benefit under the state's Medicaid home and community-based waivers, including a Sec. 1915c Medicaid waiver for children and youth with severe behavioral conditions.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)



## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Tennessee Commission on Aging and Disability (TCAD)**

Funding Period: **2014-2017**

Primary Goal: **Expand and enhance respite resources, opportunities for respite services, and invest in strategies to sustain respite for all family caregivers in Tennessee.**

Key Performance Measures	Notable Achievements
<p>Data collected on lifespan respite includes: expanded training of respite volunteers; number of hours provided through vouchers; number of hours of respite provided by volunteers; extent of engagement and dissemination of the state lifespan respite plan; and number of calls to the Statewide Respite Helpline.</p>	<p>To provide respite training and expand respite service availability, the Tennessee Respite Coalition (TRC) established one-on-one partnerships with several churches, a group of local ministers, and an Intentional Older Adult Ministry Group. TRC offered the groups Respite Education and Support Tools (REST) respite provider training and helped them design or expand caregiver and care recipient support tailored to their communities' needs.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Expand respite service delivery.</b></p> <ul style="list-style-type: none"> <li>As a result of the grant, 144 additional caregivers were provided with 13,278 hours of respite through Tennessee's Voucher Program.</li> </ul> <p><b>Objective 2: Increase the availability of trained respite providers statewide.</b></p> <ul style="list-style-type: none"> <li>Using the REST curriculum, a Master training (train the trainer course) was provided to seven Family Caregiver Coordinators from across the state so that they could provide training to local providers.</li> <li>REST training was also provided to Senior Companions and volunteers at a local United Methodist church.</li> <li>The Aging and Disability Resource Center (ADRC) in Upper Cumberland collaborated with Tennessee Technological University to train and support social work interns on respite provision. Through its cooperative education program, the University gives \$500 stipends to interns who provide 80 hours of respite after receiving 25 hours of respite training.</li> <li>Through word-of-mouth in the community and connections with Faith-Based and Community Initiatives in the Office of Minority Health, TCAD and TRC are working directly with a variety of faith-based groups to help them expand volunteer respite in their communities.</li> <li>The project staff worked with social work and occupational therapy programs to ensure that caregiver support and respite are part of their professional training curricula.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Tennessee Respite Coalition (TRC) is a statewide nonprofit organization that provides services across the lifespan for all family caregivers of children or adults with special needs. TRC provides respite services through the Family Directed Respite Voucher Program and the Corporation for National and Community Service's Senior Companions Program and operates the Statewide Respite Helpline. They are a key partner in the State Lifespan Respite grant.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>Upper Cumberland ADRC, one of Tennessee's Area Agencies on Aging and Disability (AAAD)/ADRCs, developed a model for collaboration with social work students that trained the students using REST training, and provided each student</li> </ul>

**Objective 3: Improve cooperation among public, nonprofit and corporate partners.**

- The Tennessee Respite Coalition implemented an inclusive public input needs assessment via a listening tour that engaged caregivers, professionals, community partners, caregiver staff, and aging and disability network participants and staff in providing input for the state lifespan respite strategic plan.

**Objective 4: Increase community awareness of available respite resources.**

- The TRC made presentations across the state to a wide range of groups who are interested in respite or working with caregivers of individuals with disabilities and older adults, including The Arc, the Intentional Older Adult Ministry Program, and the Alzheimer's Association.
- The TRC's executive director also conducted public television and radio interviews on respite and caring for caregivers.

with a \$500 stipend as long as they would provide at least 80 hours of respite care.

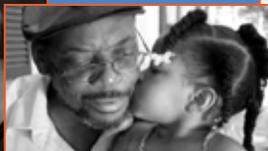
**State and Community Partners**

- Tennessee Commission on Aging and Disability (TCAD) is the state agency responsible for administering programs under the federal Older Americans Act (OAA) and for administering OAA Title III-E. TCAD administers nine Area Agencies on Aging and Disability (AAADs)/ADRCs; each has a coordinator for the National Family Caregiver Support Program. TCAD also maintains a website with information about aging and disability services.
- Tennessee Respite Coalition
- Upper Cumberland ADRC
- Tennessee Technological University



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Texas Health and Human Services Commission (HHSC)**<sup>1</sup>

Funding Period: **2014-2017**

Primary Goal: **To develop a sustainable respite care system that addresses the needs of underserved caregivers.**

Key Performance Measures	Notable Achievements
<p>Data collected include: number of caregivers receiving respite (including a focus on emergency respite); number of outreach events conducted; and number and types of stakeholders engaged to increase awareness, access and improve respite services; caregiver satisfaction with respite services; and number of respite outreach activities conducted in Hispanic/Latino communities.</p>	<p>The grantee expanded access to community-based systems of respite care in all service areas of the state; implemented respite outreach and education to Hispanic/Latino caregivers in areas with large populations of low-income and Hispanic/Latino caregivers; and integrated caregiver information into the online screening questionnaire for the Aging and Disability Resource Centers (ADRC) network.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Strengthen the Texas Respite Coalition (TRC)<sup>2</sup> and Texas Lifespan Respite Care Program (TLRCP).</b></p> <ul style="list-style-type: none"> <li>• The Texas Lifespan Respite Care Program (TLRCP), which was established by state statute in 2009, expanded respite programming into areas that had no resources or had limited access to care.</li> <li>• ADRCs across the state, and particularly in rural areas with fewer resources, engaged respite stakeholders in local steering committees – using an Asset Based Community Development needs assessment process – to develop, implement and make recommendations for sustaining respite programming at the community level.</li> <li>• TLRCP staff support the Take Time Texas website which houses respite and caregiver best practices and the state’s largest searchable database of respite providers. TLRCP staff worked with Health and Human Services web services staff to make updates to the site that will streamline the new respite provider listing process and keep the current provider list up-to-date. The website allows visitors to email the TLRCP staff via a respite mailbox.</li> </ul> <p><b>Objective 2: Increase integration of respite into the Long-Term Services and Support (LTSS) system.</b></p> <ul style="list-style-type: none"> <li>• HHSC collaborated with the Department of State Health Services to successfully integrate questions about caregivers’ needs into the screening process. Direct referrals for respite</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• TRC consists of 17 agencies and organizations, including state agencies that offer respite, nonprofit and advocacy groups, disability organizations, faith-based and for-profit respite providers, and family caregivers. TRC represents caregivers of children, older adults, individuals with Alzheimer’s, Multiple Sclerosis, Intellectual and Developmental Disabilities (IDDs), and individuals with medical conditions.</li> <li>• TRC assists HHSC in developing strategies to reducing barriers in accessing respite, improving quality of respite, reaching underserved populations, and providing training, education and support to family caregivers.</li> </ul>

<sup>1</sup> This grant was originally administered by the Texas Department of Aging and Disability Services (DADS) and transitioned to the Texas Health and Human Services Commission (HHSC) on September 1, 2016, as part of a legislatively mandated consolidation of Health and Human Services agencies.

<sup>2</sup> The Texas Respite Advisory Committee was created in 2016, under Texas Administrative Code Title 40, Rule 89.7, and replaced the Texas Respite Coalition.

care services became part of the LTSS system to prevent or delay institutionalization of older adults and persons with disabilities.

- ADRC staff received enhanced training on respite to enable them to provide needed referrals to respite along with information and referral to any necessary LTSS.
- TLRCP staff and partners conducted more than 120 local and state level outreach and education events to promote respite care as part of integrated LTSS. Outreach was conducted to health care professionals, state and local government agencies, and caregivers seeking or utilizing respite care services.

**Objective 3: Increase funding and technical assistance to create affordable respite care.**

- Grant funding supported expansion of respite services to all ADRC service areas.
- The ADRCs and a network of community partners delivered 37,063 hours of direct service respite care to 993 caregivers of children, youth, and older adults with physical, intellectual and cognitive and developmental disabilities. Respite care services were offered through new nonprofit providers that included summer camps and emergency respite programs.

**Objective 4: Increase outreach to low-income and Hispanic/Latino caregivers.**

- TLRCP conducted respite outreach and education to Hispanic/Latino Caregivers – particularly those in border areas and other communities with large populations of low-income and Hispanic/Latino caregivers. To make outreach and education relevant, TLRCP staff conducted focus groups across Texas comprised of diverse racial, ethnic and socio-economic backgrounds. The focus groups reviewed draft outreach materials and provided feedback on topics such as readability, multi-ethnic inclusion, and Spanish language translation.
- ADRCs partnered with organizations using Spanish-speaking promotor(a)s already working closely at the community level with Hispanic/Latino caregivers to incorporate respite education and referrals into community events, health fairs and education programs.
- A new respite outreach brochure was developed to better reach caregivers of diverse racial, ethnic and socioeconomic backgrounds. The brochure was produced in English and Spanish.

**Aging and Disability Resource Center (ADRC) Role**

- All 22 ADRCs in Texas were involved in activities to meet project objectives.
- HHSC funds and oversees ADRCs administered through the Older Americans Act programs. HHSC provides a continuum of LTSS for older persons and persons with disabilities. HHSC Office of Aging and Disability Resource Centers implements the state funded TLRCP.
- Under this grant, ADRCs, through emergency respite programs, were able to continue providing access to services for eligible caregivers. In addition, new emergency respite programs were implemented in most remaining ADRC service areas, the majority of which did not have established programs. As a result, 993 caregivers received emergency respite services over the grant-funded period.

**State and Community Partners**

- Texas Respite Coalition (TRC)
- Texas Health and Human Services Commission (HHSC)
- Texas Association of Community Health Centers (TACHC), a nonprofit association, represents the health care safety net for Texas providers serving the uninsured and underserved. TACHC also serves as Texas' federally designated primary care association.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Virginia Department for Aging and Rehabilitative Services (DARS)**

Funding Period: **2014-2017**

Primary Goal: **Expand and embed a sustainable, coordinated system of affordable and accessible, person/family-centered, quality lifespan respite support throughout Virginia, for families who provide unpaid care to individuals of any age with any disability, chronic disease, and/or special need.**

Key Performance Measures	Notable Achievements
<p>Outcomes measures included: the extent to which volunteers and workers felt prepared to provide respite support to families; the extent to which volunteers, workers and caregivers felt that training was flexible, convenient, and easy to use; whether caregivers felt more confident and better prepared to utilize respite supports; the extent to which families receiving voucher support felt less overwhelmed, experienced financial relief, enhanced relationships, and/or reduced anxiety; increases in outreach by lifespan respite programs to rural regions and to limited English-speaking populations; demographic data; cost per respite unit data; improved understanding among employers about the impact that caregiving has on the caregiver and company; and improved understanding among legislators about the fiscal impact of caregiving.</p>	<p>Virginia Lifespan Respite Voucher Program (VLRVP), a statewide program, covered regions representing significant cultural and economic diversity, from extremely rural to large urban areas. Working with local partners, DARS provided 711 families, on average, 41 hours of respite care and reached caregivers in urban as well as isolated underserved areas, and in diverse cultural communities.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Expand/enhance respite services through an online training program.</b></p> <ul style="list-style-type: none"> <li>• DARS reported great success providing caregivers with information, education and resources through Virginia Caregiver Coalition (VCC) educational videoconferences; VCC provided 18 educational videoconferences, with 23 participants on average in attendance for each event during the funding period. Participants from across the Commonwealth are able to call in on their own or attend at one of their local VCC sites.</li> <li>• Overwhelmingly, participants “Agreed” when asked if “the information presented will be useful to [them]” for all educational presentations. Examples of program evaluation feedback include:             <ul style="list-style-type: none"> <li>▪ “Personally strengthened me with personal experiences.”</li> <li>▪ “Insightful thoughts and ideas that can be incorporated with personal life.”</li> <li>▪ “Learned about services in the community...”</li> <li>▪ “This is a resource I will provide my community organization.”</li> <li>▪ “Community information and programs were most valuable.”</li> </ul> </li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• The Virginia Caregiver Coalition (VCC) and its network of local VCC sites are key partners and provide the infrastructure to reach Virginia caregivers across the state, across geographic areas and cultural communities.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>• At the outset of project funding, 4,564 caregivers had received information and education related to respite and referrals to respite support (a 30% increase over the previous year) through Virginia’s ADRC</li> </ul>

**Objective 2: Improve statewide dissemination/coordination of respite care through ADRC and VCC networks.**

- Respite supports are listed on the ADRC service provider database, and Virginia's online caregiver solution center.
- Members of the VCC and other caregivers serve on Advisory Councils for Aging and Disability Resource Centers (ADRC) and advocate for issues related to lifespan respite. The ADRC has become a valuable resource for information on respite throughout the Commonwealth.

**Objective 3: Increase access through a Lifespan Respite Voucher Program.**

- Virginia Lifespan Respite Voucher Program (VLRVP), a statewide program, covered regions representing significant cultural and economic diversity, from extremely rural to large urban areas. Working with local partners, DARS provided 711 respite vouchers that reached caregivers in isolated underserved areas and cultural communities. Twelve percent of those benefiting from the voucher program resided in rural areas. Additionally, the VLRVP reached limited English-speaking populations with 13.2% of vouchers benefiting Asian populations, 5.3% benefiting Hispanic/Latino populations, 3.9% benefiting Multi-racial populations, and .3% benefiting Native American populations.
- Families receiving a respite voucher generally reported an improvement in their overall well-being and happiness. A few examples from client satisfaction surveys include:
  - The program "gave me peace of mind while I was away."
  - "Respite services are very expensive, so we rarely use them. This allowed us to do something special with our other two children."
  - "Thank you so much. I feel like I have been renewed."
  - "Thank you for the respite program! It helped me get a much-needed break from the stress of managing two kids with special needs."

**Objective 4: Develop/implement strategies for working with the private-sector business community.**

- The VCC Advocacy Committee worked to raise awareness through their various networks, providing education and research, but with minimal impact. This remains a priority to the VCC as they endeavor to educate employers on the impact of caregiving on both their employees and their businesses.

**Objective 5: Identify, cultivate, and secure new and sustainable sources of funding.**

- DARS and the VCC Advocacy Committee worked with legislators to increase their understanding of the fiscal impact of caregiving on Virginia's caregivers and have requested funding for caregiver support. As a result, two legislators sponsored budget amendments. Additional funding has not been awarded at this time, but the Committee's efforts will continue with the upcoming General Assembly session in January 2018. Also, DARS is spearheading a Caregiver Taskforce composed of stakeholders, including the VCC and AARP, that are identifying resources and challenges for family caregivers and will be making recommendations in a report to the General Assembly.

network as a result of a strong VCC, DARS and ADRC partnership.

**State and Community Partners**

- Virginia Caregiver Coalition (VCC), with more than 185 members across the state (an increase of 45 members during the funding period)
- ADRCs
- Area Agencies on Aging (AAAs)
- Partnership for People with Disabilities, Virginia's University Center for Excellence in Developmental Disabilities (UCEDD), affiliated with Virginia Commonwealth University (VCU)
- VirginiaNavigator, host and administrator of the Family Caregiver Solution Center, the umbrella for SeniorNavigator and disAbilityNavigator, managed through one 501(c)3 non-profit organization, and focused on supporting individuals in maintaining quality of life within their environment of choice. VirginiaNavigator provides comprehensive information on issues such as health, financial concerns, legal questions, health facilities, housing options, transportation, exercise programs, advocacy, and more.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Washington Aging and Long Term Support Administration (AL TSA), Department of Social and Health Services**

Funding Period: **2014-2017**

Primary Goal: **Lifespan Respite Washington (LRW) will strengthen its diverse community partnerships and build upon long-term sustainability in order to provide respite service options and resources statewide to unpaid family caregivers caring for persons with special needs across the lifespan.**

Key Performance Measures	Notable Achievements
<p>Washington State collected numeric data (by county) on the number of initial caregiver contacts, referral sources, vouchers applied for and received, respite hours utilized per voucher and demographic data of care recipients. Washington State also collects qualitative data providing insight about how caregivers value respite, and case studies that provide information on how respite works and challenges encountered by those providing or using respite services.</p>	<p>The lead agency and key partners expanded respite services to underserved populations, including tribal nations, through a streamlined, user-friendly voucher system. Use of vouchers, and barriers to use, are carefully examined to guide decisions about future policies and practices.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Expand lifespan respite care through the user-friendly voucher system by focusing on underserved populations and key partnerships.</b></p> <ul style="list-style-type: none"> <li>• Thirty-seven Respite Provider Agencies joined the Voucher Program providing in-home and medical in-home care, adult day programs, specialized case aides and camps, parks, and recreation programs.</li> <li>• Outreach to underserved populations included, for example, a pilot program with the Department of Health's Children with Special Health Care Needs program allowing approximately ten children per year to utilize services through respite voucher programs and collaboration with Local Health Jurisdictions (public health departments) and LRW. This partnership served as a model for other special population programs to join LRW's efforts:             <ul style="list-style-type: none"> <li>▪ Eight Tribes were involved to develop and/or expand culturally relevant respite services for kinship caregivers.</li> <li>▪ Home Senior Services received financial donations to support Snohomish County unpaid family caregivers with respite voucher funding from two local foundations, Nysether Family Foundation and Verdant Health Foundation.</li> <li>▪ A crisis nursery provided residential crisis respite services to at risk families while offering matching funds.</li> </ul> </li> <li>• During fall, 2017, with Aging and Long-Term Support Administration's (AL TSA) LR and Home Senior Services staff, the grantee worked to make the respite voucher application</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• Lifespan Respite Washington (LRW) moved through various phases since their inception in 2002, from beginning as a think tank to becoming a coalition of about 200 advocates.</li> <li>• For this grant, LRW built upon its existing respite voucher system to include focused marketing and increased services – especially for underserved populations.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>• The grantee formed training partnerships with ADRCs (known as Community Living Connections in Washington state) to help streamline information about and access to lifespan respite options.</li> </ul>

and the Lifespan Respite Voucher Family Caregiver Agreement process less cumbersome and time consuming for family caregivers, and more efficient for LRW staff and respite provider agencies. An abbreviated Lean process, a method to improve efficiency and effectiveness, facilitated by an ALTA Lean Trainer was planned and implemented with a focus on reviewing and revising the voucher process in order to increase the percentage of caregivers who follow through and receive services. As a result of discussion and multiple drafts, a revised Lifespan Respite Voucher Application form was developed.

**Objective 2: Increase LRW/Aging and Disability Resource Center (ADRC) engagement statewide with a No Wrong Door approach, including staff cross training, community outreach, and Options Counseling.**

- Being located at (hosted by) a local Aging & Disability Resource Center (ADRC) at Homage/Senior Services of Snohomish County, a natural partnership exists for the LRW Program Coordinator. Opportunities exist for internal trainings as well as mutual conversations/consultations with staff within the agency.

**Objective 3: Increase capacity for respite services and resource offerings by strengthening sustainable business model to include public/ private funding.**

- The Grant Director worked collaboratively to develop new program models and policies that support unpaid caregivers using Medicaid funding.

**Objective 4: Increase professional and constituent awareness and feedback about respite care through LRW Coalition activities.**

- About thirty coalition partners meet at least semi-annually to share local and national respite news, share concerns, and offer insights including changes within their own agencies.

- The LRW Coordinator actively participates in ADRC trainings and meetings to ensure awareness and continuity of services.

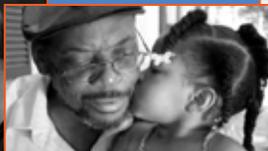
**State and Community Partners**

- Lifespan Respite Washington (LRW)
- Family Caregiver Support Program
- Area Agencies on Aging
- Developmental Disabilities Administration
- Children's Administration
- Department of Veterans Administration
- Easterseals
- Respite Provider Agencies
- Within Reach
- Parent Trust for Washington Children
- 2.1.1 Community Information Lines
- Department of Health, Children with Special Health Care Needs
- Tribal Nations in Washington State



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Maryland Department of Human Resources Social Services Administration (SSA), Office of Adult Services (OAS)**

Funding Period: **2016-2019**

Primary Goal: **Provide families caring for individuals across the lifespan and disability spectrum with knowledge and resources to support loved ones and themselves, coupled with improved and timely access to respite services, especially emergency respite care.**

Key Performance Measures	Notable Achievements
<p>Outcomes measured by the grantee include: improved and increased caregiver access to emergency respite services; increased access to qualified respite care providers; increased knowledge of caregiver information, training and supports; and the provision of alternative forms of respite. Products produced by the grantee include emergency respite services, a website containing information and resources for caregivers across the lifespan, and info-social activities.</p>	<p>Information about Emergency Respite Care, established under this grant, was made available through flyers in Spanish, Mandarin, Korean, Vietnamese, and Russian. The development of Emergency Respite Care tracking reports aided Maryland in evaluating the program.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Streamline access to respite services, especially emergency respite care.</b></p> <ul style="list-style-type: none"> <li>Maryland introduced its Emergency Respite Care Grant in late 2017 through an established private care agency that has provided lifespan respite services statewide for over six decades. Emergency respite encompasses a broad range of options, including in-home care and out-of-home care such as day care, assisted living, and nursing homes. Family caregivers may also choose to have a friend or family member provide care. Provision of emergency respite care is made within 72 hours of the request, and retroactive reimbursement of services is available.</li> </ul> <p><b>Objective 2: Increased caregiver knowledge of information, training, and supports.</b></p> <ul style="list-style-type: none"> <li>Maryland, with the assistance of its community partners, is developing a website containing vetted information and resources for caregivers across the lifespan. Topics on the website include disease- and disability-specific information, resource information, and access to topics of information that help caregivers increase their skills as caregivers and reduce stress.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The grantee provides updates on the Emergency Respite Grant to Maryland's Respite Care Coalition at regularly scheduled Coalition meetings, and the Respite Care Coalition provides up-to-date information about Emergency Respite Services for outreach and improved access to the broader community.</li> <li>The Maryland Caregivers Support Coordinating Council also serves in an important role as Maryland's statewide respite organization, and key partner in Maryland's Lifespan Respite Grant. The Caregivers Support Coordinating council is the primary resource for families for reliable information about respite services</li> </ul>

**Objective 3: Use of “info-socials” as an alternative form of respite in which caregivers access information and interact with fellow caregivers outside of their traditional roles as caregivers.**

- Info-socials will be established statewide which will serve caregivers across the lifespan, and will offer family caregivers social and training opportunities to improve their health, wellness, and knowledge, as well as provide care recipients a safe, therapeutic, and enjoyable experience by allowing participants to interact with each other outside of their traditional roles as caregivers. Info-socials will offer caregivers the opportunity to access information on topics of interest (such as behavior management, healthy lifestyles, legal counseling and long-term care options) as well as the ability to take a break from the stress and isolation that accompany caregiving for a loved one with a disability or illness.

and a universal application for respite services. They are also key partners in a Respite Training Consortium, and work with post-secondary education and faith-based groups to develop volunteer training.

**Aging and Disability Resource Center (ADRC) Role**

- The Aging and Disability Resource Center (ADRC) in Maryland makes information about the state-funded respite services and the Emergency Respite Grant available to the populations they serve, and they administer the National Family Caregiver Family Support Grant.

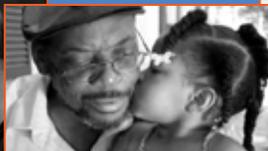
**State and Community Partners**

- Maryland Departments of Aging, Disabilities, Human Services, and Health
- Maryland Commission on Caregiving
- Maryland Family Network
- Aware of Your Care
- Kennedy Krieger Institute
- The Maryland Center for Developmental Disabilities



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **North Dakota Department of Human Services, Aging Services Division (ASD)**

Funding Period: **2017-2020**

Primary Goal: **Improve the well-being of families by coordinating existing respite systems, providing education and training opportunities, and expanding respite services.**

Key Performance Measures	Notable Achievements
<p>Data are collected to assess changes in access to information regarding respite services and resources for caregivers, and improvements in quality of respite services. Documents include a plan for continued development and sustainability of the coordinated lifespan respite system. Products include a voucher for emergency respite, and a “job fair caregiver event.” To assist in data collection for North Dakota’s environmental scan, the grantee is developing a form to assist in identifying entities that provide respite across the lifespan. Coalition members will distribute the form to their partners and contacts, and data collected will be added to the database.</p>	<p>A form has been developed and is in use for updating the Aging and Disability Resource-LINK (ADRL) database with new agencies. The ADRL is also working to include a wide array of services and agencies in the online database with the goal of having information on services and agencies across the lifespan and for all populations.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Increase awareness of existing respite services and resources for caregivers.</b></p> <ul style="list-style-type: none"> <li>ADRL resources (see Objective 2) are promoted by ASD and the Coalition.</li> </ul> <p><b>Objective 2: Streamline access to respite services through expanded use of the Aging and Disability Resource-LINK (ADRL).</b></p> <ul style="list-style-type: none"> <li>The Aging and Disability Resource-LINK (ADRL), a centralized access point for information and assistance and a beginning point for coordination of respite care and other resources for caregivers across all ages, has three components: 1) a toll free telephone information and assistance service answered by knowledgeable staff during business hours, five days per week; 2) a searchable online database (<a href="https://carechoice.nd.assistguide.net">https://carechoice.nd.assistguide.net</a>) where the public can find services available in their area; and 3) options counseling which includes a face to face visit to help consumers make decisions about their long-term care service and support needs.</li> <li>The North Dakota Respite Coalition, during their initial meeting, identified six focus areas and prioritized those into two focus areas, determining goals and objectives, during their second meeting. Subcommittees formed to work on each goal are tasked with developing a marketing plan to promote the Aging and Disability Resource-LINK (ADRL) and to simplify</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Coalition, representing individuals with disabilities or chronic conditions of all ages, family caregivers, community and faith-based organizations, and respite, social service, and health care providers, work together to promote awareness of available services as well as bring forth service needs.</li> <li>The Coalition plays an integral role in soliciting and providing information for continued identification of existing services, identifying training needs, promoting educational opportunities and services, and providing on-going input for administration, collaboration, and coordination of the grant activities.</li> </ul>

access to information on caregiving and respite care; and to explore the possibility of establishing a faith-based and/or volunteer-based respite program in North Dakota.

**Objective 3: Explore opportunities and provide education and training on caregiving and respite care for all ages, particularly in rural and underserved areas.**

- The grantee is expanding educational opportunities through the evidenced-based “Powerful Tools for Caregivers” training and a contract with a university that already provides the training. Trainings will be expanded to serve all populations, including caregivers of children with special health and behavioral needs as research indicates caregivers experience many common concerns and stresses addressed by this program.
- ASD is also contracting to provide “Caregiver Training for Native Americans” on all tribal areas of the state. Developed by the University of North Dakota Center for Rural Health through a grant from the Administration for Community Living (ACL), trainings will expand the capacity to offer education in rural areas of the state, including tribal areas, and sustain continuation of the program after the grant has ended.
- Grant funds help support caregiver education and training efforts through provision of a caregiver track at existing conferences.

**Objective 4: Develop a voucher program to provide emergency respite services.**

- ASD developed a voucher system to expand and enhance existing emergency respite services. Using a simple eligibility process administered by ASD, caregivers access emergency respite in crisis situations including, but not limited to, risk of institutional or higher level placement if respite is not provided.

**Aging and Disability Resource Center (ADRC) Role**

- The North Dakota State Unit on Aging houses the Aging and Disability Resource Link ((ADRL). The ADRL has implemented the form discussed above and is working to include a wide array of services and agencies in the online database with the goal of having information on services and agencies across the lifespan and for all populations. The Policy and Procedure manual was updated to include child-focused national agencies. The ADRL will soon be updated to a more user-friendly and mobile-friendly site focused on ADA compliance and ease of navigation. The site will include agencies and services across the lifespan. ADRL staff are working to increase knowledge of services provided to children with special needs.

**State and Community Partners**

- North Dakota State Respite Coalition
- AARP-ND
- In early May 2017, ASD and AARP-ND convened a caregiver stakeholder meeting to discuss caregiver needs in North Dakota and the opportunity to apply for a lifespan respite grant. The DHS-ASD and AARP-ND entered into a memorandum of understanding to coordinate the development of a Lifespan Respite Program and a State Respite Coalition.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **South Dakota Department of Human Services, Division of Long Term Services and Supports**

Funding Period: **2017-2020**

Primary Goal: **Improve overall access to respite services for families and other caregivers through provider development and training.**

Key Performance Measures	Notable Achievements
<p>Outcome measures include: the extent to which awareness of the availability of respite services increases; enhanced coordination between state and federal respite care programs; the sustainability of a lifespan respite coalition and increased accessibility; and utilization of respite programs serving all populations. Products include: caregiver needs assessment, marketing materials and a Lifespan Respite website with access to training resources for caregivers and providers and a searchable statewide respite provider directory.</p>	<p>South Dakota Respite Coalition formed and remains active with a wide array of state, federal and community partners and caregivers. The grantee created and distributed throughout the state a Lifespan Respite Brochure and Lifespan Respite Survey.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Collaborate with stakeholders to establish a State Lifespan Respite Coalition.</b></p> <ul style="list-style-type: none"> <li>The grantee formed a viable Respite Coalition by inviting caregivers and key stakeholders to assist in the planning and implementation of a Lifespan Respite Care Program. To enhance membership sustainability, Coalition members are directly involved in planning and implementation of ongoing activities, such as development of a marketing plan, caregiver needs assessment, respite website/respite provider directory, and a provider recruitment and training plan. Family caregivers and care recipients are invited to attend/participate in Coalition meetings throughout the project period.</li> <li>Since the inception of funding, several Respite Coalition meetings have been held, four working subgroups have been established, a mission statement and a Lifespan Respite brochure created.</li> </ul> <p><b>Objective 2: Identify and develop a plan to address programmatic barriers.</b></p> <ul style="list-style-type: none"> <li>At the state level, a collaborative planning process is identifying ways caregivers can access lifespan respite services. A State Workgroup, including Coalition members and staff from Division of Developmental Disabilities (DDD) and Long Term Services and Supports (LTSS) is working to identify systemic issues at the state level that may prevent all populations regardless of age, disability or chronic condition of the care receiver from seamlessly accessing respite services. The two State Divisions that provide and fund respite signed</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The South Dakota Department of Human Services believes that creating a Lifespan Respite Coalition brings together caregivers, service recipients and their representative organizations and agencies along with service providers and policymakers as the best approach to start a Lifespan Respite Care Program.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>The Lifespan Respite grant supports increased coordination with the state's ADRC – Dakota at Home. Program activities are designed to increase the effectiveness of the ADRC as a “No Wrong Door” for contacts from caregivers of all populations on respite care to reduce confusion on which state program to</li> </ul>

a Memorandum of Understanding to ensure coordination between programs and reduce duplication of effort in the development of lifespan respite. Each Division appointed a staff member to represent their Division and serve as a liaison to the workgroup. The State Workgroup provides state level input and technical assistance on program activities, reviews progress, and provides information to the Coalition on progress achieved.

**Objective 3: Develop a plan to recruit and train respite providers and create a respite provider directory.**

- A SD Lifespan Respite website is in the process of development to include how to access respite through Dakota at Home (ADRC) and state and federal respite programs. Information will be provided on hiring a respite provider, background checks, how to report abuse and neglect, caregiver resources and access to a respite provider application and an online respite provider directory. The directory will include individual/private respite providers in addition to agencies, assisted living, and nursing facilities available through the Dakota at Home (ADRC) Resource Directory.
- A Lifespan Respite Survey, i.e., caregiver needs assessment, was created and implemented which includes: demographic characteristics of caregiver groups receiving respite; the demand for respite; unmet respite needs including need for emergency respite; and the current usage of and unmet need for other caregiver services.

**Objective 4: Utilize Dakota at Home (ADRC) as a “No Wrong Door” for caregiver access to lifespan respite (to include new and planned emergency respite).**

- Through intake and referral, Dakota at Home (ADRC) Intake Specialists provide caregivers with information and access to state and federal respite programs including emergency respite and options planning (counseling).
- The grantee is collaborating with Active Generations (senior center) CAREgivers Program to provide trainings to state LTSS and DDD staff located across the state. Training topics include: positive aspects of caregiving; needs and challenges causing caregiver stress; signs of burnout; barriers to self-care; and how to access available community, state, and federal respite programs.

**Objective 5: Increase caregivers’ and the public’s awareness about the need for and availability of respite.**

- The Project Manager and State Workgroup are planning focus groups with and surveys of caregivers to obtain feedback about caregiver needs related to respite services; the most effective ways to reach caregivers in rural and frontier areas; and information and resources caregivers want and need. Focus groups will be comprised of prospective caregivers and caregivers using respite services, and participation will be solicited.

access and reduce caregivers making multiple calls to access respite care.

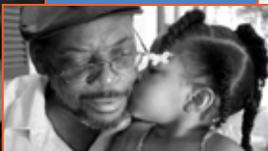
**State and Community Partners**

- Caregivers
- Division of Developmental Disabilities
- Veteran’s Administration
- AARP South Dakota
- Alzheimer’s Association SD Chapter
- Parent Connection
- Center for Disabilities
- SD Council on Developmental Disabilities
- 211 Helpline Center
- Disability Rights
- Independent Living Centers
- Assisted Living Center
- Senior Center



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Alabama Department of Senior Services (ADSS)** in partnership with **Alabama Lifespan Respite Resource Network (Alabama Respite)**

Funding Period: 2017–2020

Primary Goal: **Enhance and expand existing respite and support services to family caregivers of children and adults, while developing a policy framework that will expand and strengthen Alabama’s current lifespan respite care initiatives.**

Key Performance Measures	Notable Achievements
<p>ADSS and Alabama Respite document increases in respite use, trainings, educational workshops, public policy awareness of caregiver issues and proposed solutions. Products that document performance include: A Sustainability Plan developed by Coalition partners; Universal Voucher Guidelines; training programs and evaluation tools;; and White Paper with accompanying Comprehensive Strategic Plan. Progress and achievement of objectives are evaluated by an in-house evaluator whose specialized skills allow ADSS to develop procedures for, as well as oversee, data collection and analysis, and promote the significant impact of utilizing effective data collection.</p>	<p>ADSS, Alabama Respite and Coalition members actively promote outreach by enhancing and updating available training and educational materials, including White Papers, for dissemination. All materials are made available for review and replication on the Alabama Respite website. Stakeholders involved in the grant process are available to provide technical assistance and product sharing with other states and the ACL Technical Assistance lead. Information for consumers is available by phone through the ADRC on an established toll free number, 1-800-AGELINE, and Alabama Respite 1-888-RESTALA. This information is advertised and available for community service providers, case managers, and other agencies working with consumers and caregivers at ADSS and Alabama Respite’s websites. Materials are distributed to nonprofit, faith-based, and community organizations seeking technical assistance to implement caregiver and respite programs within their communities.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Enhance respite opportunities for all family caregivers.</b></p> <ul style="list-style-type: none"> <li>• This grant provides funds to establish a “Universal Respite Voucher” utilizing a prioritization tool to provide respite to gap populations based on those who meet the greatest need. The tool was developed as a collaborative effort within the first 90 days of the grant. Stakeholders advocate to public, nonprofit, faith-based and corporate entities to become partners in funding and expanding this Universal Respite Voucher program.</li> <li>• This grant supports expansion and start-up funding for two mini grants each year for groups that include education and technical assistance and demonstrate great potential for providing day respite programs. Alabama Respite collaborates with selected projects and other committed community stakeholders to provide substantial guidance and assistance in all phases of their projects.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• The Alabama Respite Coalition is codified by the State Legislation, and membership is appointed by the Governor. The Coalition has proven to be a unified approach of state agencies and community-based organizations to address the mandates of the Alabama Respite Act of 2006 for active stakeholders.</li> </ul>

**Objective 2: Increase and expand existing support services to caregivers utilizing existing and expanded trainings and educational opportunities.**

- Caregiver Simulation Training, an awareness and education program, is offered to non-caregivers to help them understand the challenges of caregiving and the benefits of respite.
- Lunch-n-learns, short trainings on topics such as the importance of respite and caregiver wellness, were delivered in 41 settings during a six-month period.
- Caring for those who Care, an expansion opportunity through a pilot training project, offers Assistive Technology training provided by ADSS funds through a series of local grants.

**Objective 3: Strengthen advocacy and education to public officials and policymakers to encourage implementation of expanded HCBS policies to include the caregiver and provide funding for formalized, sustainable respite and support services for caregivers.**

- As a continuation of the white paper developed by the Caregiver Taskforce designated by the Legislature, ADSS, Alabama Respite, and the Coalition support and coordinate opportunities for caregivers to educate public policy makers and communities about the growing number of caregivers and the complex issues they face. This grant supports printing and distribution of the *A Voice for Alabama Caregivers*, and provides caregivers opportunities to meet with and express their unique issues with legislators through an annual town hall forum organized by ADSS. For example, a Respite Awareness Month Proclamation was submitted and renewed, and the grantee spoke at a Legislative Forum during spring, 2018.
- To increase public policy awareness of caregiver issues and to propose solutions, ADSS collaborates with Alabama Respite to initiate an enhanced approach to data collection that builds upon quality indicators and the support of Coalition subcommittee members that informs the development of a strategic plan for an effective community-based respite and caregiver support services document that will be used to advocate for necessary changes.

**Aging and Disability Resource Center (ADRC) Role**

- ADRCs join ADSS, Alabama Respite, and Coalition members, meeting twice yearly in planning groups that report to the entire Coalition annually, in order to develop a comprehensive plan for system advancement and sustainability that expands access to information, education, support services, collaboration, and advocacy.

**State and Community Partners**

- Alabama Respite (a program of United Cerebral Palsy of Huntsville and Tennessee Valley Inc. UCP)
- Medicaid
- ADRCs
- Department of Human Resources
- Top of Alabama Regional Council of Government (TARCOG)/Area Agency on Aging's National Family Caregiver Support Program (AAA NFCSP)
- My Care Alabama
- Children's Rehab Services
- Huntsville Hospital
- Alabama Information Management System (AIMS)



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Arizona Department of Economic Security, Arizona Caregiver Coalition (ACC)**

Funding Period: **2017-2020**

Primary Goal: **Enhance current statewide respite services to provide prepaid community-based choices – fulfilling the unmet need for caregivers of low-income families by providing access to transportation and a variety of disease-, special needs-, and culturally-specific state licensed adult day health centers.**

Key Performance Measures	Notable Achievements
<p>The Arizona Caregiver Coalition (ACC) uses the Caregiver Assessment Tool (CAT) to evaluate the effectiveness of respite services and how services can be built upon and improved. The CAT (developed by Dr. David Coon of Arizona State University) includes intake information, client assessment, and pre- and post-service evaluation designed to assess caregiver features and document the benefits of respite. Outcomes included in this tool include: decreased caregiver stress, increased emotional status of the caregiver, increased medical well-being of the caregiver, increased ability and confidence for the caregiver to meet the needs of the care recipient, increased sense of support for the caregiver, increased time for pleasurable activities for the caregiver, and an increase in persons receiving respite.</p>	<p>The ACC, with funding from Easterseals and the Elizabeth Dole Foundation, created a series of Facebook ads targeting active duty military personnel and Veterans, and Veteran call volume increased by 5 percent. The ACC also launched a double-sided information flyer, “50 Things Every Caregiver Should Know,” and a series of Facebook ad campaigns. Hardcopy products were emailed, postal mailed, or hand-delivered to stakeholders.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Increase awareness, knowledge and visibility of the Day Center Respite Program.</b></p> <ul style="list-style-type: none"> <li>The grantee developed partnerships with adult day health centers through site visits and MOUs. Multiple adult day health centers agreed to waive their payment wait period, eliminating the need for caregivers to pay for services.</li> </ul> <p><b>Objective 2: Expand coordination of services by continually expanding adult day health center partnerships.</b></p> <ul style="list-style-type: none"> <li>The expansion of the current Respite Rebate Voucher Program (RRVP) is enhanced statewide to become more inclusive by partnering with multiple adult day health centers that offer a variety of programming for participants. The voucher option was discontinued in favor of the day center program, but vouchers will be added back into the program in year three of the grant. Transportation is offered by many of the day centers to assist those caregivers who have difficulty transporting their care recipient.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The ACC administers the adult day center respite program and the Caregiver Resource Line (CRL), advocates for caregivers through community outreach, partners on caregiver-related projects, and assists in legislative advocacy on behalf of caregivers. The scope of work for this grant is to expand the RRVP to include a community-based program for respite. The Day Center Respite Program partners with licensed adult day health centers throughout the state. Eligible caregivers will obtain respite from their choice of</li> </ul>

**Objective 3: Increase access to respite for most vulnerable caregiver populations.**

- DAAS and the ACC engage key stakeholder organizations, including adult day health centers, other government entities, and major nonprofit partners, in planning and implementing the respite program expansion. The target population for services includes: caregivers in rural populations, limited-English speaking populations, adults with developmental disabilities, seniors, and special diagnoses care recipients. Priority is given to Veterans and Veteran families, low-income families, and minority populations.
- The grantee is marketing to community leaders, respected elders, faith-based cohorts, social workers, and neighbors – those people who are often asked for recommendations or who give advice freely with the theory that people of influence will be able to find the caregivers who need respite help but do not know how to procure it.
- ACC is developing Spanish language materials about respite and scripts in Spanish for answering telephone inquiries.

**Objective 4: Disseminate program results.**

- In-state dissemination is on-going, including semi-annual conference calls with partnered adult day health centers and stakeholders in the project that allow the ACC to share the ongoing progress and provide opportunities for direct questions and concerns regarding the project.

center at no cost, and adult day health centers will be reimbursed by Area Agency on Aging (AAAs), which are contracted to handle the payments.

**Aging and Disability Resource Center (ADRC) Role**

- ADRCs disseminate flyers, and refer families to the ACC program.

**State and Community Partners**

- Arizona Caregiver Coalition (ACC) funded through Arizona Division of Aging and Adult Services (DAAS), administering Lifespan Respite Care Program
- Area Agencies on Aging (AAA), handling the payments for the adult day centers.
- Foundation for Senior Living, a local non-profit that funds Caregiver Resource Line (CRL), the statewide, toll-free resource line
- Adult day health centers throughout the state



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Colorado Department of Human Services, State Unit on Aging, Colorado Respite Care Program (CRCP)**

Funding Period: **2017-2020**

Primary Goal: **Advance the State of Colorado's systems and capacities to deliver respite care and related services to family caregivers of adults or children with disabilities or special health care needs.**

Key Performance Measures	Notable Achievements
<p>Colorado's Advancing Lifespan Respite grant is evaluated internally during the first two years and will be evaluated externally the final year. CRCP outcome measures, including indicators, metrics, and products, focus on: completing a Work Plan; documenting lessons learned; and delivering proposed products. The CRCP working with the Respite Care Task Force project is conducting a cost-benefit study to evaluate the financial impact of respite care services.</p>	<p>CRCP leverages state and local funding streams and partnerships to bring lifespan respite to a statewide scale. State general funds totaling \$350,000 support community respite grants, family respite vouchers, training and education.</p> <p>CRCP partners with one No Wrong Door pilot program by serving on its advisory committee, and by providing respite resource and referral trainings to pilot partners.</p> <p>CRCP received a grant from the Rose Community Foundation to create a toolkit, available as a book and online, to help families and professionals better understand how to navigate Colorado funding streams for respite services.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Further advance a sustainable, statewide system for respite care services.</b></p> <ul style="list-style-type: none"> <li>• CRCP, implementing Task Force recommendations, is working on policies: to help streamline Medicaid Waivers, to improve access to services and simplify center-based regulations; and explore relationships with health insurers to investigate the inclusion of respite services as an insurance benefit.</li> <li>• Colorado completed training for the evidence based, train-the-trainer, Stress Busting Program for Family Caregivers of Persons with Dementia preparing 12 Master Trainers in six different Area Agency on Aging regions covering 17 counties.</li> <li>• Having identified training addressing caregiving for persons with behavioral challenges as a service gap in Colorado, CRCP partnered with JFK Partners to provide a five-part webinar series focused on practical strategies for addressing challenging behaviors.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• The statewide Colorado Respite Coalition (CRC) and the Chronic Care Collaborative (CCC) provide input, expand reach, and support CRCP systemic efforts.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>• The CRCP works with 16 Colorado ADRCs to improve respite referrals and expand resources to families by sharing respite and caregiver resources. The CRCP also offers annual informational webinars to ADRCs.</li> </ul>

**Objective 2: Improve and expand statewide collaborative partnerships with relevant stakeholders.**

- CRCP leverages their prior work on their respite website (which includes financial information, resources, training opportunities, and a respite provider locator) by making the website mobile responsive, completing annual technical updates, and creating an online database of training opportunities.
- CRCP is increasing the engagement of faith communities by developing a resource toolkit.
- CRCP continues its Employer Engagement Program, disseminating a caregiver wellness toolkit, and engaging employers to modify their workplace culture to offer caregivers greater flexibility.
- CRCP partners with AARP's Colorado Caregiving Ambassador, Jane Barton, to cosponsor training around a variety of caregiving issues including grief, self-care, and embracing the aging process. Training has reached 918 caregivers through 18 training sessions for varied populations and communities, including rural settings.
- Training on recognizing disabilities, barriers and solutions was provided to college students who earned college credits through a partnership with Adams State College. Students complete 40 hours of classroom work and 11 weeks of hands-on training at the Easterseals Colorado Rocky Mountain Village Camp.

**Objective 3: Further develop and deliver each of the five required, and where appropriate, three optional respite care services, as stipulated in the Lifespan Respite Care Act of 2006.**

- CRPC continues its respite voucher program, contracting with 23 providers, and offering resources to unserved and underserved family caregivers including targeting special populations.
- The CRC website matches families with providers and maintains a database of caregiver trainings statewide.
- CRPC continues its *Coming Up for Air* weekend and education program for special needs populations, providing caregivers with training on financial planning, respite resources, and personal health and wellness.

**State and Community Partners**

- Easterseals Colorado
- Government appointed Respite Care Task Force
- Five Regional Respite Coalitions (RRCs)
- Colorado Traumatic Brain Injury Trust Fund Program
- Developmental Disabilities Council
- University Center for Excellence in Developmental Disabilities JFK Partners
- MindSource, Colorado's Department of Human Services state brain injury program
- Parkinson's Association of the Rockies
- Osher Lifelong Learning Institute
- Adams State College
- Dementia Friendly Government Sector
- Bell Policy Center



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Idaho Commission on Aging (ICOA)**

Funding Period: **2017-2020**

Primary Goal: **Expand access to respite services for family caregivers and strengthen Idaho's policy framework to support and sustain the program.**

Key Performance Measures	Notable Achievements
<p>The grantee measures increases in the number of caregivers accessing respite information and arranging respite services; the existence of a statewide standardized respite training; increases in the number and type of agencies providing caregivers with respite information; and increases in respite options for family caregivers. In addition, the grantee is producing the following products: a central respite database; lessons learned from implementation of faith and nonprofit based respite models; toolkit materials for caregivers and providers; respite training curriculum; consumer-directed respite pilot service requirements, monitoring tool, and outreach and marketing materials; an employer respite information and supports assessment results.</p>	<p>Utilizing survey and assessment data gathered over a three-year period, the ICOA/ICA (Idaho Caregiver Alliance) published the <i>Idaho Lifespan Caregiver Action Plan (Plan/Action Plan)</i> in October 2016. The Plan, which gained unanimous support from the 2017 Idaho Legislature, includes objectives to enhance the state's lifespan respite system and funding strategies.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Coordinate and strengthen lifespan respite systems at the State and local levels.</b></p> <ul style="list-style-type: none"> <li>• The ICOA's 2018 State Strategic Plan includes implementing the Action Plan, sustaining the ICA, and continuing to develop and enhance lifespan respite including: working with policy makers to improve social, financial, and supportive services environments for caregivers across the lifespan by providing a strong, credible voice for caregivers.</li> <li>• The ICA was involved in two significant legislative efforts during the 2018 legislative session, including testifying in favor of the Idaho Department of Licensing and Certification proposed rule changes for the Certified Family Homes (CFH) program, and sponsoring a dialogue about issues related to the Patient Caregiver Support Act, a bill sponsored by AARP Idaho based on the C.A.R.E. Act adopted in many states.</li> <li>• The ICA convenes quarterly progress meetings, develops respite workshops for state or regional conferences, and coordinates with the ICOA to develop a statewide central respite database.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• In 2013, the ICOA was awarded a Lifespan Respite grant for new states from the Administration for Community Living, which fostered the growth of the Idaho Lifespan Respite Coalition, now known as the Idaho Caregiver Alliance (ICA). The ICA, led by Dr. Sarah Toevs at the Boise State University Center for the Study of Aging (BSU-CSA), is a robust and active stakeholder group of over 400 individuals and agency members. The ICOA/ICA participates on the Idaho Healthcare Coalition, the oversight body for the State Health Innovation Plan (SHIP), creating person-centered medical homes</li> </ul>

- The ICOA/ICA created a respite registry workgroup including members from Idaho Department of Health and Welfare (IDHW) Money Follows the Person/Idaho Home Choice, Children’s Mental Health, and Family and Children’s Services to create respite registry/central directory parameters; purchase or develop a platform; and populate and market the platform to caregivers and providers statewide. Based on research conducted with other state registries, the ICOA/ICA are pursuing other priorities and opportunities.
- BSU-CSA in coordination with the Idaho Public Health Association hired a part-time BSU student intern to publish a weekly Legislative Update.

### Objective 2: Provide innovative respite services to family caregivers.

- The ICOA sought the participation of an AAAs/ADRC to establish a consumer-directed lifespan respite program pilot with an emphasis on the underserved target population. No AAA/ADRC has the capacity to establish the program. Other alternatives are being pursued, including the ICOA establishing the program. An objective of this process is to develop business practices that are easy for the caregiving family to use, the respite worker to navigate, and the AAA/ADRC to manage.
- The ICOA is building a consumer directed portal into an existing management information system, allowing the Information and assistance staff at the AAA/ADRCs to automate service approvals for consumers.
- BSU-CSA created a Respite Project Coordinator role to engage a Respite Workgroup by soliciting general members and recruiting representatives from Idaho Division of Behavioral Health at the state level, Idaho Division of Family and Children’s Services at the regional level, and a nonprofit entrepreneur developing a sensory camp for adults with traumatic brain injuries.

### Objective 3: Increase the level of knowledge and professionalism in respite care by providing training to caregivers, providers, and volunteers.

- The ICOA researched and selected existing core (common elements across the lifespan) and specialized (culturally specific, specific to particular health conditions, or specific to a respite model, like volunteer respite) training for caregivers, providers, and volunteers. Training is available on ICOA’s website and accessible through the Live Better Idaho and 211 Careline websites, and access is promoted through IDHW to Medicaid providers and through the ICA and their constituencies. In 2018, IDHW expanded Certified Family Home Providers roles to include community adult day services.
- The Caregiver Integration Project, part of Idaho’s Statewide Healthcare Innovation Plan (SHIP), a multi-year grant funded project to transform primary care practices to patient-centered medical homes, held an event during December, 2017, called “Coordinating Resources Across the Lifespan” attended by more than 50 primary clinic staff. Attendees gathered at tables and listened to caregivers and community health workers share stories about the benefits to caregivers of engaging with primary clinic staff, enabling the caregiver to take better care of herself/himself and the person in their care. Evaluation results from the event showed that the majority of participants experienced increased awareness of the role of unpaid caregivers, and they received adequate information to recognize and refer caregivers to supports, including access to respite.

(PCMH) through primary care system transformation. The ICOA/ICA was also instrumental in creating a pilot project to integrate caregivers into the PCMH.

### Aging and Disability Resource Center (ADRC) Role

- The ICOA administers the National Family Caregiver Support Program (NFCSP) to provide respite to eligible consumers through the six state AAA/ADRCs.
- The ICOA contracts with six community-based nonprofit organizations to develop and implement lifespan respite programs targeting underserved populations in each of the AAA/ADRCs Planning and Service Areas. The AAA/ADRCs assist with marketing to the local community-based respite programs.

### State and Community Partners

- The ICOA contracts with Boise State University-Center for the Study of Aging (BSU- CSA), to continue as lead agency for the ICA.
- Idaho Department of Health and Welfare (IDHW) Divisions of Medicaid (Money Follows the Person/Idaho Home Choice), Behavioral Health and Public Health
- 211 Careline
- Idaho Parents Unlimited
- IDHW Navigators and Regional Medicaid Units
- Idaho Healthcare Association
- Community Partnerships of Idaho
- MS Society
- Critical Access Hospitals
- Jannus Inc, Legacy Corps

**Objective 4: Enhance access to lifespan respite care information by establishing new information access points in addition to the Area Agency on Aging/Aging and Disability Resource Centers.**

- The ICA is creating a toolkit with uniform messaging and training for distribution statewide through local channels utilizing the ICA network. The toolkits will equip access points like the AAA/ADRCs, 211 Careline, Idaho Parents Unlimited, IDHW Navigators and Regional Medicaid Units, the Idaho Healthcare Association (private long-term care providers), Community Partnerships of Idaho, the MS Society, Critical Access Hospitals (CAH) and Easterseals of Idaho with essential respite information for lifespan caregivers.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)



# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Nevada Aging and Disabilities Services Division (ADSD)**

Funding Period: **2017-2020**

Primary Goal: **Strengthen support and services for family caregivers in Nevada through advocacy and capacity building.**

Key Performance Measures	Notable Achievements
<p>The grantee collects data on: increases in the number of people served through public programs; increases in funding across the lifespan; and the percent of caregivers receiving respite services having more choice and control in their services. Products developed include: caregiver intake forms; respite enrollment applications; and respite pre- and post-surveys.</p>	<p>A Department of Health and Human Services (DHHS) workgroup is working to identify data sources for respite, to conduct a “strengths, weaknesses, opportunities and threats” (SWOT) analysis, and to share products and methodology to streamline grant processes. In Year 2 of the grant, the group will focus on data and outcomes as well as funding streams.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Coordinate respite services across state partners to expand capacity across the lifespan.</b></p> <ul style="list-style-type: none"> <li>The Nevada partners are working together to overcome common barriers associated with different eligibility criteria across programs, database compatibility, client confidentiality, and conflicting requirements imposed by diverse funding sources.</li> <li>The Project Coordinator worked with Nevada Lifespan Respite Care Coalition (NLRCC) to develop a vendor call for facilitation of group activities that would strengthen the membership, increase partnerships, and build capacity. Working with the Coalition, ADSD contracted with Turning Point, Inc. to support coalition-building efforts. As part of its activities, Turning Point organized the NLRCC retreat, which led to membership-identified key objectives and activities around respite that will both support and strengthen the coalition, and lead to short term and long-term achievements on its path to sustainability.</li> </ul> <p><b>Objective 2: Strengthen the Nevada Lifespan Respite Coalition to provide advocacy and education of respite in Nevada.</b></p> <ul style="list-style-type: none"> <li>The Nevada Lifespan Respite Coalition, a key advocacy partner for respite services in Nevada’s No Wrong Door implementation, is working to organize stakeholders, including competing providers, to create a strong voice for Nevada’s caregivers.</li> <li>The Nevada Aging and Disability Services Division, in partnership with the Nevada Lifespan Respite Coalition, is working to identify a sustainable structure and expand membership that supports education and advocacy, expands the Coalition’s efforts to diversify membership and engage stakeholders, and enhances their involvement in the state’s lifespan respite program.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The Nevada Lifespan Respite Coalition, a key advocacy partner for respite services in Nevada’s No Wrong Door implementation, is working to organize stakeholders, including competing providers, to create a strong voice for Nevada’s caregivers.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>As part of the implementation efforts, ADSD conducts refresher training for the Nevada Care Connection Resource Centers (ADRCs). As the designated entities to provide person-centered counseling and caregiver support services in Nevada, the Resource Centers are uniquely positioned to help caregivers identify the full range of respite and other caregiver support services available in Nevada.</li> </ul>

**Objective 3: Expand self-directed respite services to underserved populations including those in rural areas and adults with disabilities.**

- ADSD is piloting a self-directed voucher program that will give caregivers a small monthly allotment to hire their own workforce. The voucher will focus on weekly respite, with options to save a portion of the monthly allotment for a larger respite break (such as a day camp). ADSD is also working with other respite programs under the Department of Health and Human Services (DHHS) to identify data to be used in a comparison study.
- The voucher program will be provided to an estimated 62 families for 12 months. Each family has a budget of up to \$308 per month for respite services. ADSD branded this program as Respite Rx.
- The Project Coordinator began outreach for the Respite Rx voucher program. Outreach efforts were facilitated through local community groups such as the Nevada Lifespan Respite Coalition, Nevada Dementia Friendly Community Action Groups, Regional Planning Groups, and through connecting with various individual organizations throughout Nevada.

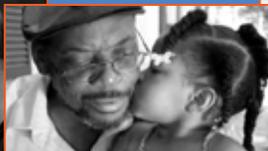
**State and Community Partners**

- Nevada Respite Coalition
- Department of Health and Human Services, Office of Community Partnerships and Grants
- Division for Healthcare Financing and Policy (Nevada Medicaid)



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **New York State Office for the Aging (NYSOFA)**

Funding Period: **2017-2020**

**Primary Goal:** The Lifespan Respite Core Team (Core Team) will build upon prior and current Lifespan Respite initiatives by engaging key stakeholders to increase and expand access to respite services statewide, and enhance partnerships for education, outreach, and service provision to advance development of a Lifespan Respite Care System.

Key Performance Measures	Notable Achievements
<p>NYSOFA documents statewide implementation of the REST (Respite Education and Support Tools) training model (with a goal of 100%); 30% increases in REST Companion volunteers (with a goal of 30% over baseline); increases in the number of individuals that receive information and assistance on caregiver supports through NY Connects; increases in knowledge about caregiving through Caregiver Simulations among nine higher education institutions and three private sector business entities; and the completion of a qualitative review of respite listings in the NY Connects Resource Directory.</p>	<p>The NY Connects Resource Directory includes regular data feeds on long-term services and supports (LTSS) providers and programs from the NY Department of Health, Office for People with Developmental Disabilities, Office of Mental Health, and Office of Alcoholism and Substance Abuse Services, adding to the aging network listings already in the Directory for a current total of over 72,000 program listings. This activity is part of NY Connects' expansion to a No Wrong Door (NWD) system that now provides statewide coverage of information and assistance on LTSS to individuals across age and disability types, their caregivers, and helping professionals (<a href="https://nyconnects.ny.gov">https://nyconnects.ny.gov</a>). The New York State Caregiving and Respite Coalition (NYSCRC) developed a new brochure highlighting its mission, information about the Virtual Resource Center, and other available services.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Increase number of respite volunteers through additional training and recruitment activities.</b></p> <ul style="list-style-type: none"> <li>New York State uses a multi-strategy approach to assisting families and caregivers by supporting respite through expansion of the evidence-supported REST program. Additionally, NYSOFA assisted in outreach efforts to RSVP programs in targeted geographic areas to further expand the REST model across the state.</li> <li>In December 2018, NYSCRC awarded two mini-grants of \$3,500 each to further develop and/or expand the Volunteer Respite programs in faith-based organizations. Awardees are Grace Lutheran Church in Broome County, and Greece Baptist Church in Monroe County. Grace Lutheran is developing a "Senior Care Respite Program," which will provide an opportunity for caregivers to drop off their loved one at the program once a month, providing relief for caregivers in the Vestal, NY area. Greece Baptist Church is developing a "Give Me a Break" Drop off Respite program that will also be hosted monthly and serve caregivers in Greece,</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The New York State Caregiving and Respite coalition, part of the core team guiding and administering the lifespan respite grant, is also a key partner in establishing a Lifespan Respite Resource Center that will make available a suite of evidence informed/evidence-based training services, the Caregiver Simulation model for education with new partners in higher education and the private sector, as well as other materials and respite-related resources.</li> </ul>

NY. Both dedicated faith communities are committed to using REST to train and support their volunteers.

**Objective 2: Expand available respite services statewide through formalizing a caregiver-directed respite model.**

- NYSOFA reconvened its consumer-directed work group previously formed under the 2014-2017 Lifespan Respite Initiative and is well underway in developing a formal “caregiver-directed” respite services model using funds under the Older Americans Act (OAA) Title III-E program. This optional model for Area Agencies on Aging (AAAs), will offer greater flexibility with a person-centered approach for caregivers to identify and help address their respite needs.

**Objective 3: Expand access to caregiver services through improved respite listings in the NY Connects Resource Directory across age and disability types.**

- NY Connects, New York’s No Wrong Door “hub”, provided consistent, comprehensive, locally-based information on long-term services and supports to consumers, caregivers, and families to help them make informed choices, and assisted them in linking to services across service systems. During the first six months of funding, approximately 4,000 caregivers contacted NY Connects for assistance each month, and more than half of those caregivers received information on available respite services. Data show that caregiver supports continue to rank in the top third of topics being requested in NY Connects.

**Objective 4: Implement and continue to update the Statewide Action Plan for Lifespan Respite sustainability.**

- The Core Team hosted a Lifespan Respite Sustainability State Summit with invited participants to undertake strategic planning work on Lifespan Respite Sustainability during the Fall, 2018.
- The NYSCRC Director continues to ‘build’ the Lifespan Respite Virtual Resource Center (VRC), housed on the NYSCRC Website by adding new resources and training tools as identified through partnerships with key stakeholders. New resources added to the VRC this reporting period include the AARP Leading Age Change Report; the Legislative Update on Care Corps Demonstration Act; listings of caregiver workshops hosted by Lifespan of Greater Rochester; Generations United Grandfamilies Fact Sheet; and ARCH Fact Sheet for caregivers of persons with Intellectual Developmental Disabilities.

**Aging and Disability Resource Center (ADRC) Role**

- Aging and Disability Resource Center Role
- NYSOFA, a core team member for this grant, is the state agency responsible for administering programs under the federal Older Americans Act (OAA) and for administering NY Connects (ADRC/NWD), and other state-funded LTSS programs. New York Connects has primary responsibility for maintaining the NY Connects Resource Directory of community-based long-term services and supports.

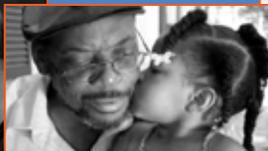
**State and Community Partners**

- The Lifespan Respite Core Team (Core Team) is comprised of the: New York State Office for the Aging (NYSOFA), Monroe County Office for the Aging (MCOFA), New York State Caregiving and Respite Coalition (NYSCRC), and New York State’s ADRC/NWD (NY Connects).
- Additional partners include: faith-based organizations to bring respite into underserved communities; RSVP to help build a pool of respite volunteers; and NYSCRC and higher education to establish a Lifespan Respite Resource Center.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **North Carolina Division of Aging and Adult Services (DAAS)**

Funding Period: **2017-2020**

Primary Goal: **Advancing state systems and capacities to deliver respite care and related services to family caregivers of adults and children with special needs.**

Key Performance Measures	Notable Achievements
<p>Data collected will document the extent to which the state system of public and private partnerships supports community living and recognizes the value of person-centered options, respite, and caregiver inclusion; the extent to which online and telephone information and assistance services effectively inform and connect caregivers with respite resources across the lifespan and across the state; and the extent to which procedures and best practices for consumer-directed respite voucher providers and programs are improved. Products include a survey tool for providers to inform consumer-directed respite voucher programs; educational materials for providers and caregivers on maximizing efficiencies and overcoming barriers; a report outlining best practices for a respite voucher program; and call center staff training materials and protocols for optimum interaction with caregivers seeking resources.</p>	<p>North Carolina is working to expand the No Wrong Door partnership between the Division of Aging and Adult Services and United Way 2-1-1 by increasing the quantity and quality of respite resources available for caregivers through the 2-1-1 system and by enhancing training on respite resources for 2-1-1 Call Center staff. Recognizing the importance of a No Wrong Door approach to long-term services and supports, the NC General Assembly appropriated funding for a full-time position within DAAS to partner with United Way 2-1-1 for statewide information and assistance with access.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Improve the state’s consumer-directed respite voucher programs at the systemic level for both family caregivers and providers.</b></p> <ul style="list-style-type: none"> <li>In North Carolina, grant funding is used to impact caregivers and providers who interact with these vouchers, regardless of how the vouchers are funded. Because getting caregivers to accept and hire help is a learning experience for many, they need support initially. North Carolina’s intervention aims to systemically improve the practice and policies for consumer-directed respite voucher programs, thus enhancing the effectiveness and ease of use for respite providers, paid and volunteer staff, caregivers, and their loved ones.</li> </ul> <p><b>Objective 2: Strengthen the capacity of North Carolina’s statewide information and assistance network to more fully and accurately respond to caregivers’ resource and respite inquiries.</b></p> <ul style="list-style-type: none"> <li>North Carolina is working to expand the No Wrong Door partnership between the Division of Aging and Adult Services and United Way 2-1-1 by increasing the quantity and quality</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>North Carolina’s respite coalition ceased to operate functionally in 2017. The State’s Lifespan Respite Advisory Team and the Jordan Institute for Families at UNC’s School of Social Work have been fulfilling the functions of this organizational role.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>North Carolina’s respite voucher program is administered by DAAS and a AAA with special expertise in operating a caregiver foundation.</li> </ul>

of respite resources available for caregivers through the 2-1-1 system and by enhancing training on respite resources for 2-1-1 Call Center staff.

- Recognizing the importance of a No Wrong Door approach to long-term services and supports, the NC General Assembly appropriated funding for a full-time position within DAAS to partner with United Way 2-1-1 for statewide information and assistance with access.

**Objective 3: Expand the referral network of the direct service respite voucher program to increase access to respite for caregivers in identified gap populations across the state.**

- The grantee is working to maintain or increase voucher use annually and target populations found to be least connected to accessible respite services. This includes updating materials related to client confidentiality and waiting list policies, and increasing the number and capacity of referring agencies, including United Way 2-1-1, by working with members of Lifespan Respite State Advisory Team to broaden the referral network of direct service respite providers by 1) sending team members a sample e-mail with specific information on the Lifespan Respite Voucher program with marketing materials attached, and 2) requesting that they share that information with providers in their networks.
- The AAA respite voucher contractor is also increasing outreach activities.

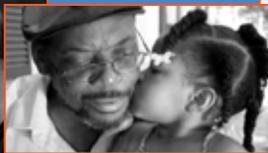
**State and Community Partners**

- United Way 2-1-1
- Project Advisory Team (with 60 members actively engaged in the activities and direction of the lifespan respite program)



For more information, contact ARCH at (703) 256-2084 or [jkgagan@archrespite.org](mailto:jkgagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Oklahoma Department of Human Services, Aging Services (OKDHS AS)**

Funding Period: **2017-2020**

Primary Goal: **Expand, enhance, and ensure the sustainability of gap-filling respite services to Oklahoma family caregivers across the lifespan and disability spectrum.**

Key Performance Measures	Notable Achievements
<p>Measurements include the extent to which respite vouchers are easily accessible and manageable by caregivers; and the extent to which the partnership with Oklahoma Aging and Disability Resources Consortium/No Wrong Door (okADRC/NWD) results in streamlined access to valuable resources. Additional performance measures include increases in public/private partnerships, and improvement in caregivers' health. Policy development events to promote caregiving services and nurture sustainability will be documented. Additional outcomes anticipated include: refreshed, informed caregivers; a respite voucher program; an easy to use online searchable database; productive public/private partnerships; an employee caregiver training; an increase in respite support; and a comprehensive final program report.</p>	<p>The Oklahoma Caregiver Coalition (OCC) Executive team and respite subcommittees are taking part in a strategic planning process to expand and sustain respite services in Oklahoma with the help of a strategic planner. The strategic plan will include securing a nonprofit entity as a fiscal and administrative sponsor or gain 501(c)(3) status for the OCC to expand caregiver services and activities.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Advance existing lifespan respite services statewide.</b></p> <ul style="list-style-type: none"> <li>Oklahoma's 2017 Lifespan Respite Grant (LRG) funds "On The Road" (OTR) training bringing caregiving providers (many are OCC partners) together to share resources and services to caregivers and care recipients in strategically placed urban and rural locations across the state. One OTR training in a rural county took place through a fruitful partnership with the Comanche Nation. Caregivers report that the best thing about OTR trainings is that they leave with names and contact information of individuals who can assist them in readily accessing resources.</li> </ul> <p><b>Objective 2: Actively collaborate with the Oklahoma Caregiver Coalition (OCC) to provide supportive respite services.</b></p> <ul style="list-style-type: none"> <li>OCC partners with approximately 130 family members, care recipients, and public and private agencies across the state. OCC meets quarterly to provide updates on respite programs; share success stories; coordinate limited resources; discuss marketing strategies; review possible funding sources; and maintain contact with partners. Each partner is assigned to one of the nine OCC subcommittees.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The grantee's key partner is the statewide Oklahoma Caregiver Coalition (OCC) with approximately 130 Oklahoma partners providing supportive caregiver services. A partnering agency is the Oklahoma Aging and Disability Resources Consortium/No Wrong Door (okADRC/NWD).</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>okADRC/NWD is housed in OKDHS Aging Services (AS) and works closely with Area Agencies on Aging (AAAs), Centers for Independent Living, Developmental Disability Services (DDS),</li> </ul>

**Objective 3: Develop policies and strategies to sustain access to respite services.**

- Due to limited resources and the lack of Oklahoma legislators agreeing on how to solve Oklahoma's fiscal crisis, many state-funded services and supports are shrinking or disappearing. Oklahoma leaders, including the Governor and five state agency chief executives, have joined together to develop a plan for a "No Wrong Door" system for Oklahoma that connects individuals to a full range of community services and supports. The Lifespan Respite Grant Manager has been involved in planning the development of a web portal named "Oklahoma Supports" that will provide resources to the aging, mental health, and developmental disabilities populations. Since these populations rely heavily on caregivers, it is important that caregivers' needs be considered as the statewide web portal is being developed. The web portal will be a valuable link on the website being designed for Oklahoma caregivers.

**Objective 4: Evaluate and disseminate program results.**

- The Lifespan Respite Grant Voucher Program developed pre- and post-surveys, and applying caregivers are required to complete the pre-survey along with their application for services. After caregivers have submitted a voucher for payment, a post-survey is sent to the caregivers. Almost 100% of pre- and post-surveys are returned.

and other agencies to build and expand a collaborative network. Five of the major state health and human services agencies are developing a web portal to include an online resource directory for caregivers.

- OKDHS AS provides funds from the Older Americans Act (OAA) and National Family Caregiver Support Program (NFCSP) to the AAAs for respite programs. The AAAs provide respite services in their Planning and Service Areas based upon needs assessments to identify services needed in their communities.

**State and Community Partners**

- Oklahoma Caregiver Coalition
- Veterans Administration
- Department of Mental Health
- AARP
- Office of Disability Concerns
- 2-1-1 (a statewide information and referral system providing information on respite and helping caregivers navigate services)



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Rhode Island Department of Human Services/Division of Elderly Affairs (DEA)**

Funding Period: **2017-2020**

Primary Goal: **Integrate, bring to scale, and achieve long-term sustainability of Lifespan respite services in the State.**

Key Performance Measures	Notable Achievements
<p>The grantee's Evaluation Plan will measure: 1) improvement in access to, and awareness of, respite care programs as measured through enrollment data and number of individuals educated on the existence of and process for accessing respite care programs; 2) the number and types of individuals receiving information and education on the Caregiver Alliance of Rhode Island; 3) caregiver and nursing student satisfaction with the nursing student respite initiatives; 4) the number of nursing students trained to provide respite services and the number of families served by the nursing students; and 5) the growth, success stories, and deliverables of the newly incorporated Caregiver Alliance. Planned products include a nursing student respite training toolkit for replication; the development of a State Plan for Caregiver Support; and respite locator tool to be deployed on United Way of Rhode Island (UWRI) and Department of Elderly Affairs (DEA) websites.</p>	<p>Each partner agency is responsible for collecting and reporting applicable data to the DEA and Healthcentric Advisors, a nonprofit healthcare quality improvement organization, on a quarterly basis. Specifically, each nursing program conducts their own evaluations as part of already established requirements, and shares their data with the group. The Modified Caregiver Strain Index (MCSI) is an example of one evaluation tool used in assessing caregiver outcomes. Healthcentric Advisors will use the data to track the various metrics and will provide DEA and its partner agencies with quarterly reports. Analyses will be performed and conducted in accordance with Healthcentric Advisors' analytic policies and procedures, to ensure data protection and implement work-check procedures that ensure quality of the analyses.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Expand the Rhode Island student nursing workforce development initiative among higher education nursing programs in the state.</b></p> <ul style="list-style-type: none"> <li>DEA previously established a workforce development initiative with Rhode Island College (RIC) and University of Rhode Island (URI) nursing programs that offers student nurses clinical experience and course credit while being matched with low to moderate income families who have no access to subsidized respite care. Building off the successful implementation of targeted training and respite placement programs of nursing students at RIC and URI, DEA is expanding to include nursing programs at New England Institute of Technology (NEIT) and Salve Regina University (SRU). Long-term, the goal for sustainability is that each nursing program can continue this initiative at little to no cost.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>DEA is acting to solidify the Caregiver Alliance of Rhode Island by funding a position to lead, support, represent, and advocate on behalf of the Caregiver Alliance. DEA will task the Caregiver Alliance to help further develop Rhode Island's framework and respite service system.</li> </ul>

**Objective 2: Enhance the framework of the State's respite program through the newly incorporated Caregiver Alliance.**

- The Caregiver Alliance of Rhode Island was incorporated and obtained 501(c)(3) status in 2017 as a subsidiary under United Way of RI (UWRI), the State's lead ADRC partner and operator of THE POINT. The Caregiver Alliance maintains independence from UWRI, but enjoys the benefits of nonprofit status through association. DEA is taking actions to solidify the Alliance by funding a position to lead, support, represent, and advocate on behalf of the Caregiver Alliance. DEA will task the Caregiver Alliance to take specific actions to help further develop the framework and system of respite service in Rhode Island. By the end of the third year of the grant, the Caregiver Alliance will be a formalized and self-sustaining entity, have produced a State Plan for Caregiver Support, and produced a set of basic competencies to be required of respite care providers.

**Objective 3: Improve awareness about respite services and access to respite services, to include continued funding of the CareBreaks respite program that was implemented under a previous Lifespan Respite grant.**

- Grant funds help pay part of the respite care costs for families with low to moderate income who have no access to any other program for subsidized respite care through the CareBreaks respite program, established during the previous grant period. CareBreaks is the primary recipient of Title III E National Family Caregiver funds and RI state funds designated for respite services. In addition to the framework of service currently implemented by CareBreaks, DEA is working with Catholic Social Services (CSS) of RI to expand its partnership of referrals to more CEDARR Family Centers and enhance focus on group respite activities as an approach to manage increased costs and a shortage of homecare workers in Rhode Island.
- DEA also will work with UWRI to look at the feasibility of developing a volunteer peer-to-peer program for new parents of children with special health needs to be partnered with families who have experience in the process already.

**Aging and Disability Resource Center (ADRC) Role**

- The Rhode Island ADRC has been a partner in the Lifespan Respite projects since its inception. THE POINT, operated by UWRI, is a key operating partner within the Rhode Island ADRC system and serves as an accessible walk-in and call-in portal for the ADRC. These statewide call-in and walk-in centers continue to serve as the focal point for family caregivers, and DEA staff continues its work with the ADRC and UWRI to ensure that families have access to comprehensive information on respite care and caregiver support and access to assistance with application preparation and service delivery.

**State and Community Partners**

- Caregiver Alliance of Rhode Island
- United Way of Rhode Island (UWRI)
- Catholic Social Services of Rhode Island (CSS)
- Rhode Island College
- University of Rhode Island
- New England Institute of Technology
- Salve Regina University



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **South Carolina Department on Aging (SCDOA), Community Resources Division**

Funding Period: **2017-2020**

Primary Goal: **Develop new public and private partnerships that further expand and strengthen SC's coordinated lifespan respite system engaging a broader cross-section of stakeholders for future sustainability.**

Key Performance Measures	Notable Achievements
<p>Outcome measures will document: expansion of state public/private partnerships supporting caregivers and sustaining SC's Lifespan Respite System; increases in awareness of respite, assessment and identification of caregivers; increases in awareness of the need for respite, how to support families, and action involving respite through faith-based or other systems of care; increases in the number of families receiving respite; and new knowledge on Lifespan Respite that will contribute to the fields of aging, disabilities, and lifespan respite. Products include video, infographic, brief caregiver assessment tool, respite solutions conference for faith communities, and increased respite through mini-grants for "Break Rooms" to faith-based programs.</p>	<p>In their Respite State Plan, the State Committee on Respite (SCOR) members identified user-friendly educational products and strategies that are being developed with grant funding: a 2-3 minute video explaining respite, its benefits, and how to use respite vouchers and other respite services; an infographic highlighting the importance of respite and directing caregivers to key respite resources; and a brief caregiver assessment tool for physicians to use to identify caregivers in need of respite. In partnership with the University of South Carolina's Journalism School Create-A-Thon competition, a series of information items (e.g., posters, information cards for physician offices, bumper stickers, billboards and radio spots) have been developed. In addition, mini-grants have been issued to four churches to develop "Break Rooms" for respite for family caregivers in their congregations/communities. Two have begun providing respite.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Expand and strengthen the involvement of key state and local public and private stakeholders from across the age and disability spectrum as full partners.</b></p> <ul style="list-style-type: none"> <li>Grant funding supports South Carolina in maintaining momentum and expanding coordination of the Lifespan Respite System by more fully engaging key public stakeholders like Medicaid, South Carolina Department of Disabilities and Special Needs (SCDDSN), and Long-term Care (LTC) Taskforce, as well as new partners (i.e., business leaders, health care providers, faith communities, and service organizations) to build a more sustainable system of care.</li> <li>The grantee and partners are working to leverage new partnerships and to transform the State Committee on Respite (SCOR) and Regional Councils into a formal member coalition expected to continue beyond the grant. The grantee is working to broaden membership at the state and regional levels to include private and public partners. Utilizing the newly updated and released Lifespan Respite State Plan as a guide, the partners are developing a strategic plan to recruit new members to the State Committee on Respite (SCOR) to assist in implementing specific recommendations. Initial focus is to recruit leaders from business,</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The South Carolina Respite Coalition (SCRC) is responsible for: expanding partnerships and stakeholder engagement across the state through existing and new Regional Councils; developing video and other materials, and disseminating those materials via the website, and partner networks; planning and conducting the faith community conference; and delivering respite services through the voucher program. The SCRC Executive Director oversees all program and financial operations and prepares reports submitted to SCDOA.</li> </ul>

health care and education. Potential member organizations identified include the Public Employee Benefit Authority (PEBA) and Lutheran Family Services, which operates a “respite house” in the greater Columbia area for consumers of the SC Department of Disabilities and Special Needs (DDSN) as well as consumers of Community and Long-Term Care (CLTC).

- The grantee is working to strengthen the two Regional Councils and add a third in the eastern Pee Dee area to broaden outreach, develop local networks for expanded respite services, and promote lifespan respite across the state.

**Objective 2: Provide tools to increase awareness and understanding of the need and benefits of respite.**

- As specific informational tools to increase awareness are developed (see Notable Achievements), partners work through and support other organizations to infuse respite into the dialogue and garner support for development of new respite resources. Examples include: radio interviews; Memory Care classes; and coordination with SCDDSN for recruitment and training of respite providers.

**Objective 3: Develop respite services and recruit respite providers, paid and unpaid, in faith communities.**

- The grantee and partners are reviving the annual Respite Solutions Conference for Faith Communities in order to re-engage faith groups in the Lifespan Respite System. The first conference, guided by Regional Councils, is planned for Year 2 of the grant in one region, with a second conference planned for Year 3 in a second region. Conferences will educate faith communities, particularly “gate keepers” (e.g., pastoral visitors, care team leaders, parish nurses) on how to: identify family caregivers in their midst; coach family caregivers to use respite early and often; and stimulate development of respite services by sharing models of faith-based respite (e.g., voucher programs, respite co-ops, care teams, adult day care programs, respite events and inclusive child and adult care).
- Regional Councils are engaging faith communities as partners in providing the “Caregiver Respite Events” around the state.
- Mini-grants have been awarded to four (with three more to be awarded in 2019–2020) faith groups to develop Break Rooms. Two have opened and started providing respite.

**Objective 4: Fill gaps/increase availability of respite by providing vouchers across the lifespan using lessons learned to inform policy development and strategies to sustain and increase access to respite services beyond the life of the grant.**

- The LR Voucher program uses a small amount of grant funding to fill service gaps, targeting new families who have not used respite, fill in during funding shortfalls, and explore use of vouchers to increase flexibility in respite options for families. Efforts are coordinated with other voucher programs (through joint meetings, AIM reporting database, and frequent contact) to ensure efficiency and avoid duplication. Lessons learned from these interactions are being analyzed to inform policy and develop strategies to sustain these efforts.

**Aging and Disability Resource Center (ADRC) Role**

- The SCDOA/AAs provide respite vouchers through the Family Caregiver Support Program (FCSP), State Voucher Program, and the Alzheimer’s Voucher Program, in total serving 3,740 family caregivers in FY2017 with 256,382 hours of respite.
- ADRCs are central to SC’s Lifespan Respite System and connecting family caregivers to respite and other support services. ADRCs participate on State/Regional Councils and coordinate with Family Connection and SCRC to provide Information and Referral/Assistance to families.

**State and Community Partners**

- South Carolina Respite Coalition (SCRC)
- ADRCs
- Family Connection
- South Carolina Department of Disabilities and Special Needs (SCDDSN)
- Faith-based organizations



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Tennessee Commission on Aging and Disability (TCAD)**

Funding Period: **2017-2020**

Primary Goal: **Respond to the needs determined by the community conversations held under the current Lifespan Respite Care Act funding.**

Key Performance Measures	Notable Achievements
<p>Data will be collected to document the number of respite providers completing training by the end of project period; the accessibility of providers to family caregivers; and increases in the number of calls to the Statewide Respite Helpline over baseline FY2017 (762 calls); the number of respite vouchers provided to caregivers per project year; and caregiver outcomes as a result of using respite services (with a goal of 80% of caregivers using respite reporting a reduction in stress and the desire to utilize respite again). Products include a business plan and proposal by year 2 of funding; the completion of four meetings with potential business funders of respite vouchers and the finalization of a relationship with one of the four to increase respite voucher funding for caregivers; a respite provider training registry system; and marketing materials.</p>	<p>Tennessee Respite Coalition (TRC)'s easy to locate and navigate website, <a href="http://tnrespite.org">tnrespite.org</a>, offers a universal online application for respite services, and a caregiver survey. The TRC website also connects the broader community with respite through opportunities to become involved – individual and business sponsorships; volunteering; financial and material donations; and through notification of respite events.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Establish a standard training curriculum for respite providers in Tennessee.</b></p> <ul style="list-style-type: none"> <li>In partnership with Tennessee Tech University (TTU), the grantee is exploring curricula and training delivery methods, including technology supported training.</li> <li>The TRC entered into a three-year agreement with TTU to create a respite training video.</li> </ul> <p><b>Objective 2: Create a seamless system for family caregivers to access trained providers.</b></p> <ul style="list-style-type: none"> <li>The TRC entered into a three-year agreement with TTU to construct a statewide system via website to provide a storehouse for information and products generated by the grant.</li> </ul> <p><b>Objective 3: Promote current respite services to caregivers and the general public.</b></p> <ul style="list-style-type: none"> <li>The TRC entered into a three-year agreement with TTU to design a 360-degree visual experience for smart devices.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>In June 2017, the Tennessee Commission on Aging and Disability (TCAD) and the TRC hosted four community conversations and opened an online survey to help assess the needs of caregivers across the state. The results will be used to guide grant activities, including the development of a statewide respite plan.</li> <li>The TRC, a key partner in the grant, is a nonprofit organization that supports statewide respite services; manages the Family Directed Respite Voucher Program statewide and the Corporation for</li> </ul>

**Objective 4: Increase the availability of respite vouchers for all caregivers.**

- The TRC was on target in 2018 to serve 150 caregivers with respite vouchers.

National and Community Service Senior Companions Program in Davidson County; maintains a comprehensive list of respite resources across the state; and operates the Statewide Respite Helpline. The TRC provides services across the lifespan for all family caregivers of children or adults with special needs.

**Aging and Disability Resource Center (ADRC) Role**

- The Tennessee State Plan on Aging 2017–2020 includes strategies for partnerships between the Area Agencies on Aging and Disability (AAAD)/ADRCs and TRC to ensure that the National Family Caregiver Support Program (NFCSP) focuses on the needs of caregivers by providing respite and other long-term services and supports (LTSS) to families. TCAD oversees and ensures that the AAAD/ADRCs use standardized protocols for dissemination of information, assistance, and referrals to federal- and state-funded LTSS.

**State and Community Partners**

- Tennessee Respite Coalition (TRC)
- Tennessee Tech University (TTU)



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Washington Aging and Long-Term Support Administration (AL TSA)**

Funding Period: **2017-2020**

Primary Goal: **Washington Aging and Long-Term Support Administration (AL TSA) and Lifespan Respite Washington (LRW) will strengthen the respite system to become more sustainable while expanding to specialized populations.**

Key Performance Measures	Notable Achievements
<p>Data collected on lifespan respite outcomes includes increases in respite service options tailored to the needs of Traumatic Brain Injury survivors and their caregivers and access to American Indians/Alaska Natives across the lifespan as evidenced by funding availability; new service options and number of users; increases in caregiver outreach opportunities; increases in timely utilization of caregiver vouchers; and commitment by one or more public/private partnerships to provide financial support for ongoing LRW services.</p>	<p>AL TSA staff held a Respite Round Table with representatives of the state's Developmental Disabilities Administration, Aging and Long-Term Support Administration, Family Caregiver Support Program, and LRW. The Round table provided a venue to acquire information from respite provider agencies about their programs and unique challenges and resulted in a WA Respite Care Information Matrix outlining the formal respite services available within the state respite system (located on the LRW website).</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Enhance respite services.</b></p> <ul style="list-style-type: none"> <li>• Develop respite options to underserved populations. During the initial year of funding, LRW/AL TSA advanced efforts to increase respite service options tailored to the needs of individuals with traumatic brain injury (TBI) and their caregivers, and American Indians and Alaska Natives (AI/AN), including making a presentation at the Washington State Traumatic Brain Injury Council Conference in May 2018, and using a Tribal specific lifespan respite survey to better understand the needs of Tribal caregivers.</li> <li>• Create online respite options/planning modules. Online respite options and planning modules are placed on key partners' websites to increase knowledge and access to LRW. Each of the online modules designed by AL TSA's Instructional Developer provide information on what respite is, ways it could be used, how both the caregiver and recipient can plan to get the most out of the respite opportunity, along with what services are available.</li> <li>• Train public/private service systems. In the first year, half-day trainings on the WA Assistive Technology Act Program Technology for Independence were available for LRW and its partners conducted through collaboration with the Aging and Disability Resource Centers (ADRCs). LRW and AL TSA staff presented workshops/poster sessions at various conferences (e.g., TBI statewide annual conference, National Lifespan Respite Conference, annual Tribal Money Follows the Person Conference and a Kinship Care Conference).</li> <li>• Utilize ADRC system for LRW data.</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>• Lifespan Respite Washington (LRW), founded in 2002, has served as lead on four prior Lifespan Respite ACL grants and continues offering leadership on this grant.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>• ADRCs are key partners in the Assistive Technology Act Program Technology for Independence.</li> <li>• The grant will utilize ADRC system for LRW data.</li> </ul> <p><b>State and Community Partners</b></p> <ul style="list-style-type: none"> <li>• Aging and Long-Term Support Administration</li> <li>• Department of Social and Health Services Developmental Disabilities Administration and Children's Administration</li> </ul>

**Objective 2: Evaluate respite capacity and efficacy.**

- Conduct respite provider/user surveys. The first year of the program focused on gathering feedback on specific and overall respite service systems with five surveys targeted to: TBI survivors and caregivers; AI/AN caregivers; caregivers of individuals with Developmental Disabilities (DD) on no-paid services caseload; and previous lifespan respite care voucher recipients along with respite providers.
- Analyze survey data for access/consistency/quality. The grantee collects and reports data on voucher use including: demographic information, referral source, number of vouchers awarded, total amount authorized and used, average voucher amount, and also collects qualitative data exploring reasons caregivers chose not to use vouchers.
- Create issue briefs. Department of Social and Health Services (DSHS) researchers and ALTSA staff design, implement, analyze, and develop issue briefs on the results of the surveys to evaluate access, consistency, recommendations of next steps and LRW quality.
- Evaluate LRW's processes to increase efficiencies.

**Objective 3: Strengthen infrastructure and sustainability.**

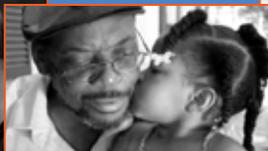
- During the initial year of funding, ALTSA entered into a contract with Senior Services of Snohomish working as "Homage", administering and managing the Lifespan Respite Washington Voucher Program, providing respite outreach and training, assisting with sustainability, and completing reports and evaluation. During the second year, the organization, Partnerships and Action, Voices for Empowerment (PAVE) became the new home for LRW, and added executive support, data management and reporting.
- Increase respite services. In year three, LRW is contracting with TBI organizations to provide education about the value of short breaks for caregivers of people with TBI. Home care agency workers will be trained in TBI basics to increase use of paid caregivers in the TBI community. A pilot project has begun in three Washington tribal home care agencies to train tribal staff members on respite services so they in turn can educate tribal members about the importance of short breaks for caregivers and assist tribal members to apply for vouchers and choose care providers.
- Improve access and utilization of LRW vouchers. LRW vouchers totaling \$75,000 are available in each year of the grant. In year one, there would be a combination of new grant funds and third year LR Sustainability Grant funding (requested of ACL through a no-cost extension).

- Department of Veterans Administration
- Family Caregiver Support Program in partnership with 13 Area Agencies on Aging
- Centers for Medicare and Medicaid Services
- Traumatic Brain Injury organizations
- Managed Care Organizations
- Health Home, County Public Health
- Operation Family Caregiver
- Washington State Tribes



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Arkansas Division of Aging and Adult Services (DAAS)**

Funding Period: **2018-2021**

Primary Goal: **Achieve systems-level changes which will support and sustain program coordination and service provision.**

Key Performance Measures	Notable Achievements
<p>Anticipated project outcomes and products include: increased legislative awareness of respite needs for greater impact on policy; outcome data from legislative respite study supports will be used to guide the creation of a state respite office; a state respite voucher program for family caregivers, and a manual and quality assurance protocols will be developed; respite sustainability plans created at annual workshops; an increase in the number of trained respite workers; and increased respite awareness.</p>	<p>In an expanded effort to provide information and outreach, the grantee revised the Arkansas Lifespan Respite Awareness Infographic and Fact Sheet; updated the Arkansas Lifespan Respite and Caregiver Resource webpages and embedded them in the Arkansas Department of Human Services (DHS) website; and developed the Arkansas Respite Locator Spreadsheet, available to the public on Arkansas's Caregiver Resources webpage. An example of one respite resource supported by Lifespan Respite subgrant dollars is an innovative 10-week Yoga for Caregivers program that provided caregivers with yoga instruction, stress relieving exercises, and fellowship with other caregivers while their loved ones received care in the same building to ease caregivers' concerns. Certified yoga instructors experienced with special needs and elderly populations, a therapist, nurse and volunteers worked in concert to provide 479 hours of respite care to 31 caregivers.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Increase legislative awareness of respite needs in Arkansas for greater impact on policy.</b></p> <ul style="list-style-type: none"> <li>Partners for Inclusive Communities at Arkansas's University Center on Disabilities will offer expertise in working with legislators to help guide this process. An information packet will include the Arkansas Lifespan Respite Coalition (ALRC) brochure, a list of respite services in Arkansas, a report from the online respite survey, and other Arkansas respite facts.</li> <li>Legislators will be invited to the Annual Arkansas Lifespan Respite Awareness Day at the state capitol, which will include an overview of respite needs in Arkansas, family caregivers sharing their stories, and presentations from key legislators who have had personal experience with being a caregiver. Invited speakers from states that have passed respite legislation will point out the benefit of developing policy to support and sustain a statewide lifespan respite system in Arkansas.</li> </ul> <p><b>Objective 2: Develop a state respite voucher program for family caregivers.</b></p> <ul style="list-style-type: none"> <li>The state respite voucher program through this grant funding will be subgranted to four organizations representing populations that span all ages and individuals with special needs</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>In addition to the Arkansas Lifespan Respite Coalition being a key partner in this grant, the Executive Director of Partners for Inclusive Communities, Arkansas's University Center on Excellence in Disabilities, currently serves as Chair of the Arkansas Lifespan Respite Coalition.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>The Choices in Living Aging and Disability Resource Center (ADRC) located in the Arkansas Division of Aging and Adult Services (DAAS), in partnership with the Arkansas Lifespan Respite Coalition</li> </ul>

across the disease and disability spectrum. A voucher program manual will be developed by the grant program manager to provide guidance to subgrantees, and subgrantees will receive regular site visits to monitor quality assurance. To sustain the respite voucher program, proposed legislation to fund a state respite office designates a portion of the requested funds to provide direct lifespan respite services through a respite voucher program managed by the state respite office.

**Objective 3: Conduct annual sustainability workshops with a facilitator to help plan future growth of the statewide respite system.**

- Annual sustainability workshops will be conducted in order to develop a plan for future growth and sustainability of the statewide respite system. As a guide for the workshops, the Sustainability Planning Workbook by The Finance Project will be used to help develop a comprehensive sustainability plan with a focus on mobilizing community support and cultivating leadership. A Caregivers Conference will bring caregivers, legislators, coalition members and other stakeholders together to share ideas, and services and support information.

**Objective 4: Continue volunteer respite trainings.**

- Continuing the Respite, Education and Support Tools (REST) volunteer respite training events around the state will allow faith-based and community respite organizations to send volunteers for quality training. This objective builds on past partnerships with the University of Arkansas for Medical Services (UAMS) Schmieding Family Caregiver Training Program to provide the needed training sites and trainers to conduct eight REST trainings each grant year. Based upon “lessons learned” from earlier REST training events, community and faith-based respite programs that specifically recruit and use volunteers in their programs will be targeted for the trainings.

**Objective 5: Conduct ongoing marketing activities to increase the public’s awareness of respite.**

- The Aging and Disability Resource Center (ADRC) website will continue to present information to increase awareness of respite and ways to access services. Health fairs, senior center events and rural development conferences will provide opportunities for presentations about the ALRC, its activities and services. The ALRC brochure developed during the 2014 grant and other promotional items will be distributed at the events. DAAS will subgrant in grant years two and three to a select entity to conduct four regional respite awareness events across the state in an effort to mobilize community support and cultivate leadership for growing a statewide respite infrastructure. A respite media campaign in grant years two and three will provide greater community awareness and serve to build support for respite legislation.

(ALRC), comprised of key stakeholders, work collaboratively to expand and strengthen the current Lifespan Respite Program and develop a policy framework to assure long-term support and sustainability of a statewide Lifespan Respite System.

**State and Community Partners**

- Partners for Inclusive Communities, Arkansas’s University Center for Excellence on Disabilities
- Arkansas Lifespan Respite Coalition
- CareLink
- Area Agency on Aging of Northwest Arkansas
- Area Agency on Aging of Southeast Arkansas
- Easterseals Arkansas
- Arkansas Parent Advisory Council Inc.
- University of Arkansas for Medical Sciences, Donald W. Reynolds Institute on Aging
- Arkansas Autism Resource and Outreach Center
- Community Connections
- Fellowship Bible Church
- Pediatrics Plus
- Arkansas Families First
- Therapy Providers
- Kid Life Plus, New Life Church, Greater Little Rock
- AARP
- The Frank and Barbara Broyles Foundation
- National Alliance on Mental Illness (Arkansas)
- Lonoke County Council on Aging
- Arkansas Total Care
- Empower Healthcare Solutions



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

# Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Massachusetts Department of Developmental Services (DDS)**

Funding Period: **2018-2021**

Primary Goal: **To leverage experience and expertise found in state agencies and Massachusetts Lifespan Respite Coalition (MLRC) community partners in a strategic way to increase the capacity to serve individuals eligible for state agency services and the wider constituency who would benefit from respite.**

Key Performance Measures	Notable Achievements
<p>Data collected includes: increase in consumer access to respite services; increase in knowledge of best practices in respite care among respite care providers; increase in the diversity of Massachusetts Lifespan Respite Coalition (MLRC) collaborators; increase in sustainability of respite providers; and improvement in the employers' capacity to recognize and support the role of respite for their employees. Products include a replicable model for states to evaluate the collaboration and effectiveness of a strategic alliance of state agencies providing respite; a blueprint for statewide respite training for relevant partners; a replicable respite training model; and an enhanced provider directory on the Rewarding Work website.</p>	<p>Massachusetts formed a statewide strategic alliance comprised of eight state agencies providing respite services. They also completed a comprehensive environmental scan of state agency respite services, funding, data tracking, and community partners, and conducted a baseline evaluation of level of integration among strategic alliance members.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Increase awareness by family caregivers on how to access respite services.</b></p> <ul style="list-style-type: none"> <li>The MLRC Advisory Group will explore and share the current delivery practices and potential gaps in MA long-term services and supports, state respite programs and options. The overarching goal of the Lifespan Respite Advisory Group will be to review existing programs across agencies and develop an action plan in response to the identified limitations and barriers with a goal to improve state-funded family caregiver services across programs.</li> </ul> <p><b>Objective 2: Increase the number of qualified respite providers.</b></p> <ul style="list-style-type: none"> <li>Developing an infrastructure to train future, diversified groups of respite providers is key to increasing the capacity. The initial task will be the development of an interagency respite training subcommittee as part of the MLRC to share training approaches. MA proposes using an existing Executive Office of Elder Affairs (EOEA) respite volunteer curriculum, recently adapted from the MA Personal and Home Care Aide State Training direct care worker training. The curriculum is available in English and Spanish. The goal of the EOEA Respite</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>This project builds upon previous work of the Massachusetts Lifespan Respite Coalition (MLRC) and aims to align with existing regional coalitions throughout the state to conduct outreach to current and potential respite providers in their region, develop recruitment strategies for volunteer opportunities and identify best practices.</li> <li>The Massachusetts Lifespan Respite Coalition (MLRC), a key partner in the grant, promotes and supports access to quality respite care options that enhance the lives of individuals and families with special needs throughout the lifespan.</li> </ul>

Provider Training is to provide respite information for seniors who desire an opportunity to “give back” to the community through volunteerism.

- The EOEA Respite Provider Training will conduct pilot trainings at two regional Retired Senior Volunteer Programs (RSVP) with an expected outcome of 20 trained senior respite volunteers (10-trained volunteers at each RSVP). Assessment of the training outcomes will provide vital information for improving the training.

**Objective 3: Share strategies to develop and promote respite service across state agencies.**

- MLRC continues to increase access to respite providers through the development of the Rewarding Work online respite directory. Building on the history of the MLRC, this project will refocus the meeting structure/agendas to support the achievement of Objectives 1 and 2. The Coalition and Advisory Group will share best practices, identify common issues, and strategize on methods to collaborate and leverage scarce resources.

**Objective 4: Track availability and utilization of respite provided by state agencies.**

- The MLRC Advisory Group will seek to establish a common definition for respite services across state agencies and identify existing and possible measures to track respite service availability, utilization, expenditures and outcomes across state agencies.
- The MLRC Advisory Group will discuss strategies to incorporate the impact of respite services of caregivers as part of state agencies’ training for new and incumbent employees.

**Aging and Disability Resource Center (ADRC) Role**

- Representatives from the Massachusetts Aging and Disability Resource Consortia (ADRCs) are members of the MLRC.

**State and Community Partners**

- MLRC is led by a broad range of experts and advocates, including family caregivers, leadership from state health and human service agencies, and providers of home, health and personal care. Members include (but are not limited to) representatives from:
  - Developmental Disability Services (DDS)
  - Massachusetts Executive Office of Elder Affairs (EOEA)
  - Mass Health Office of Long Term Care (OLTC)
  - Massachusetts Executive Office of Health and Human Services (EOHHS)
  - Massachusetts Department of Mental Health (DMH)
  - Massachusetts Department of Public Health (DPH)
  - Massachusetts Department of Children and Families (DCF)
  - Massachusetts Rehabilitation Commission (MRC)
  - University of Massachusetts Medical School
  - Massachusetts Aging and Disability Resource Consortia (ADRCs).



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency:

**Montana Department of Public Health and Human Services (DPHHS), The Aging Services Bureau, Senior and Long Term Care Division**

Funding Period: 2018-2021

**Primary Goal:** To advance the Montana Lifespan Respite (LR) Coalition by strengthening the framework to ensure sustainability for the provision of services and related supports that are easily accessible to family caregivers of children or adults with special needs.

Key Performance Measures	Notable Achievements
<p>Data are collected on the number of formally trained family caregivers, providers and volunteers; the extent to which there is improved access to trained caregivers through a respite registry; increases in the use of the respite voucher program, and in the use of the sustainable Montana LR Program. Products of the grant include: a caregiver training program; a respite registry; marketing and outreach materials; a faith-based caregiver education model; and annual respite summits.</p>	<p>The information gathered through the Lifespan Respite Summits helped shape the activities of the LR Coalition and launch the media campaign and statewide Lifespan Respite Voucher Program.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Offer training to family caregivers and potential respite providers.</b></p> <ul style="list-style-type: none"> <li>The LR Coalition collaborates with the Montana State University Extension’s Powerful Tools for Caregivers (PTC) program, a six-week educational program to teach informal caregivers better self-care. The program has expanded curriculum for informal caregivers of those with chronic illness, parents of children with special needs, and grandparents raising grandchildren.</li> </ul> <p><b>Objective 2: Develop respite registry of trained individual providers utilizing the Aging and Disability Resource Center (ADRC) Resource Directory.</b></p> <ul style="list-style-type: none"> <li>ADRCs/Area Agencies on Aging (AAAs) are working collaboratively with the grantee to add a respite registry to the common searches of the ADRC Resource Directory.</li> </ul> <p><b>Objective 3: Support outreach efforts to best educate caregivers and providers about Lifespan Respite.</b></p> <ul style="list-style-type: none"> <li>The grantee is engaged in an ongoing statewide awareness campaign to ensure caregivers, providers, agencies and individuals are knowledgeable of the importance and need for respite services. Public service announcements (PSAs) have been shown to be very effective</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>The State Lifespan Respite Coalition is a key partner in strengthening Montana’s statewide Lifespan Respite Care System to include a sustainable policy framework to continue provision of respite and related supports to family caregivers across the lifespan. This grant builds upon the coalition’s previous work.</li> </ul> <p><b>Aging and Disability Resource Center (ADRC) Role</b></p> <ul style="list-style-type: none"> <li>ADRCs/AAAs are working collaboratively with the grantee to add a respite registry to the common searches of the ADRC Resource Directory.</li> </ul>

in reaching caregivers and providers across the state. Grant funds support development of new PSAs focusing on educational opportunities specific to caregivers and individual providers.

**Objective 4: Continue educational efforts of policy decision makers to secure funding for the Lifespan Respite program.**

- In 2012, the state's LR Coalition completed an environmental scan that outlines the respite funding and services available in Montana in addition to identifying unmet needs. The environmental scan revealed DPHHS Divisions have limited respite funds available for those meeting categorical and financial eligibility criteria. In collaboration with AARP, the Alzheimer's disease and related dementias (ADRD) state planning workgroup and the Money Follows the Person (MFP) program were successful in getting caregiver related questions added to the Behavioral Risk Factor Surveillance System (BRFSS).
- Data available in 2018 from the 2015 Behavioral Risk Factor Surveillance System (BRFSS) will lend strength for future funding requests. Data collected from Montana's LR Voucher program will be shared with administration, policy makers and other stakeholders. The LR Coalition is also exploring nonprofit 501 (c)(3) status. Contingent on this effort, a contribution fund will be established.

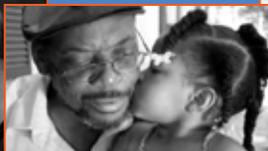
**State and Community Partners**

- Montana Lifespan Respite Coalition
- Aging and Disability Resource Center (ADRC/No Wrong Door (NWD) System) network
- County Councils on Aging
- Faith-based programs
- AARP
- Children's Trust Fund
- Montana State University



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

## Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Virginia Department for Aging and Rehabilitative Services (DARS)**

Funding Period: **2018-2021**

**Primary Goal:** Expand and enhance Virginia's coordinated system of affordable and accessible, person/family-centered, quality lifespan respite support throughout the Commonwealth, for: families who provide unpaid care to individuals, of any age, with a diagnosis of dementia; for grandparents or relative caregivers providing care to a child not more than 18 years of age or an individual 19 to 59 years of age who has a severe disability; or a relative of a child by blood, marriage, or adoption.

Key Performance Measures	Notable Achievements
<p>Data are collected to document the following identified outcomes: the number of new partnerships that provide program referrals; identification of possible alternative funding and community resources; benefits of respite as reported by caregivers; and the development of an educational series for target populations. Additionally, the Virginia Caregiver Coalition (VCC) documents activities that encourage additional membership; evidence of the State's understanding of gaps in services and resources available to caregivers; and the accuracy of data entry in the State Lifespan Voucher Assistant. The grantee generates quarterly and yearly data based reports indicating areas for program improvement. Products include: Survey of Grandparents and Relative Caregivers community resources; Pre/Post Caregiver Burden Inventory survey; a Service Gap Report; and Lessons Learned.</p>	<p>The Virginia Caregiver Coalition (VCC) began 15 years ago with 22 founding members and now numbers more than 200. VCC works to improve care recipients' and their families' experience of caregiving through education, advocacy and access to resources. The VCC highlights specific challenges inherent to targeted populations by dedicating at least one educational series to each respective population. The VCC also seeks out and encourages membership within targeted populations. Educational topics shared through regular VCC meetings have included: Unique Approaches to Double Duty Caregivers, Supporting Dementia Care Partners, Advance Directives, Managing Other Peoples' Money, Age Friendly Communities and Medicaid Expansion.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p><b>Objective 1: Increase outreach to target caregivers of individuals with dementia and grandparents or relative caregivers providing care to a child or an older individual with a severe disability.</b></p> <ul style="list-style-type: none"> <li>Virginia is enhancing their statewide lifespan respite care system by forging new partnerships with memory clinics, outpatient specialty clinics, local Alzheimer's chapters, the Healthy Grandparents Program and other kinship groups in each major geographical region of the Commonwealth as a source for referrals to better penetrate proposed target populations.</li> </ul> <p><b>Objective 2: Increase caregiver coalition capacity within target populations.</b></p> <ul style="list-style-type: none"> <li>Using the network of family caregivers, care recipients and public/private agencies within the Virginia Caregiver Coalition (VCC) in the planning and implementation of proposed</li> </ul>	<p><b>State Respite Coalition/Organization Role</b></p> <ul style="list-style-type: none"> <li>Established in 2004, the Virginia Caregiver Coalition (VCC) continues to be a strong ally for Virginia's caregivers and has boosted membership to nearly 200 agencies and family members across the lifespan, supporting individuals of all ages and disabilities. In addition, members of the VCC and other caregivers now serve on Advisory Councils for Aging and Disability Resource Connections (ADRC), advocating for issues related to lifespan respite. DARS</li> </ul>

respite care activities, a current MOU between the VCC and DARS continues a partnership of education and outreach to Virginia's caregiving community.

**Objective 3: Expand the Virginia Family Caregiver (VFC) Solution Center to include resources that assist grandparents and relative caregivers.**

- Virginia has a network of 343 strategically located VirginiaNavigator Centers that provide assistance to older adults, individuals with disabilities, and family caregivers, including Virginians who don't have a computer or internet access. These Centers are partnerships between VirginiaNavigator and community-based supports such as libraries, faith-based communities, hospitals, community centers, transportation providers and other community-based organizations, whose staff is trained to use VirginiaNavigator and its family of websites, SeniorNavigator and disAbilityNavigator. Because the Virginia Family Caregiver (VFC) Solution Center is hosted by VirginiaNavigator, the Centers' staff were trained also on the Solution Center. During 2017, the VFC Solution Center reported 588 site visits.

**Objective 4: Convene a stakeholder group to conduct a year-long gap assessment of Virginia's family caregiving issues and long-term services and supports to expand the No Wrong Door (NWD) Resource Database.**

- The grantee is convening a stakeholder group with representatives from the VCC, AARP, Commonwealth Council on Aging, Partnership for People with Disabilities, Virginia Alzheimer's Commission, and VirginiaNavigator, (in consultation with Virginia's NWD Director) to conduct a year-long assessment of the NWD Resource Database and identify caregiver resources and service gaps.

**Objective 5: Increase knowledge and use of respite among family caregivers of individuals with dementia and grandparents or relative caregivers.**

- Grant funds support expanding the VFC Solution Center to include resources for grandparents and relative caregivers. Further, this funding opportunity allows the VCC to grow as it focuses on another caregiver target and network system, strengthen their network of partners such as memory centers and kinship groups, and allow DARS to identify unmet respite needs of caregivers of individuals with dementia and grandparents and relative caregivers.

**Objective 6: Utilize the NWD System to make automated referrals, securely share individual-level data and track individual progress.**

- Applicants using VirginiaNavigator are provided information and referrals for programs and other resources, identified through person-centered practices, as a good match for their individual needs, using the NWD System.

**Objective 7: Combine gap-assessment data with NWD System data to better understand and address needs across the state.**

- This grant helps NWD incorporate referrals for respite vouchers, which allows automated referrals, secure exchange of individual-level data, and a comprehensive tracking tool and robust reporting to ensure streamlined access to the voucher program, provide ongoing support to caregivers and capture valuable data for outcome measures.

**Objective 8: Show a measurable increase in the number of families experiencing temporary relief of caregiving burden.**

- The State collects data on the benefits of respite as reported by caregivers, including the extent to which caregivers who receive voucher support feel financial relief, reduced stress

and the VCC have worked as partners for eight years to establish an integrated lifespan respite infrastructure in the Commonwealth of Virginia.

**Aging and Disability Resource Center (ADRC) Role**

- DARS Division for the Aging oversees 25 Area Agencies on Aging (AAAs).
- Members of the VCC and other caregivers across Virginia serve on Aging and Disability Resource Connections (ADRC) state and local advisory committees, advocating for issues related to lifespan respite.

**State and Community Partners**

- Virginia Caregiver Coalition (VCC)
- AARP
- Commonwealth Council on Aging
- Partnership for People with Disabilities
- Virginia Alzheimer's Commission
- VirginiaNavigator
- UVA Memory Clinic
- Riverside Center for Excellence in Aging and Lifelong Health
- Carilion Clinic for Healthy Aging
- REACH
- Healthy Grandfamilies

and/or anxiety, enhanced relationships with family members, and improved quality of life as a result of respite care.

**Objective 9: Reduce stress of caregivers of individuals with dementia and grandparents or relative caregivers.**

- Grant funds provide 450 families with vouchers worth up to \$400 to include resources for grandparents and relative caregivers.



For more information, contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)



For more information, visit [www.archrespite.org](http://www.archrespite.org)  
or contact ARCH at (703) 256-2084 or [jkagan@archrespite.org](mailto:jkagan@archrespite.org)

This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Respite Network and Resource Center.